# Joint National Committee on Aboriginal **AIDS** Education and Prevention

## Findings Document

JOINT NATIONAL COMMITTEE

ON ABORIGINAL AIDS

EDUCATION AND PREVENTION

**Findings Document**

The committee was created in 1989 to research and report its findings to the Minister of National Health and Welfare Canda and make recommendations on the issue of AIDS as it affects aboriginal people in Canada.

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# Section One: INTRODUCTION

## Introduction

The purpose of the Findings Document is to present relevant information on AIDS and the aboriginal community as a basis for a National Strategy; to report on the findings relevant to two specific research hypotheses; and to identify and describe AIDS education and prevention activities aboriginal people and others have implemented. The document describes the results of research activities undertaken during the period of March 1989 to November 1989.

The Findings section of this report is divided into three parts. The first two parts detail the research findings relative to the two research hypotheses. The third part details additional findings which have emerged over the course of the Committee's research and discussions.

The Joint National Committee developed two hypotheses to guide the research efforts necessary to support a National Strategy on Aboriginal AIDS (Acquired Immunodeficiency Syndrome) Education and Prevention for aboriginal communities. It is believed that before an effective strategy can be designed, all existing data, information and knowledgeable opinion on the subject of AIDS and aboriginal people must be analyzed and considered within the context of these two hypotheses:

1. The factors that lead to HIV infection and to the development of HIV spectrum diseases and AIDS are present within the aboriginal community.

2. There is a need for aboriginal-specific AIDS Education and Prevention programs and activities.

(A detailed description of the hypotheses and the related research framework is contained in Exhibit 1.)

A series of issues and questions were developed to address these hypotheses and all relevant documentation, literature, papers (resulting from the Call for Papers), knowledgeable opinion resulting from interviews and presentations and information provided on the survey questionnaires was analyzed based on the issues and questions outlined in the research framework.

## Other Issues Relevant to AIDS Education and Prevention:

In addition to the issues relevant to the two hypotheses articulated above, results of the Call for Papers and further research indicated the need for the Joint Committee to address issues which, while not central to

AIDS education, are important to aboriginal communities: priorities for research in native sexuality and related issues; issues surrounding HIV testing; traditional healing; and the implications of AIDS in aboriginal communities and the federal government's policy of transfer of Medical Services to First Nation governments. As much as possible, the Committee has attempted to address these issues in the third section of this document.

## Section Two: METHODOLOGY

## Methodology

Research to support the National Strategy on Aboriginal AIDS Education and Prevention began with the establishment of the Joint National Committee in March 1989 and was formalized with the drafting of the "Call for Papers" (Appendix 2) and the development of the hypotheses and the Research Framework (Exhibit 1).

An extensive review of literature and documents was undertaken over the entire research phase. Meetings with key informants were scheduled and the Consultant as well as members of the Joint National Committee participated in the discussions.

The "Call for Papers" was distributed across Canada to a number of interest groups and experts on the subject of AIDS; aboriginal organizations, agencies and service providers; federal and provincial health services departments; universities and medical researchers; AIDS support groups; alcohol and drug abuse centres; and gay and lesbian organizations. The "Call for Papers" requested the input of all interest groups on such issues as:

- prevention measures
- cultural considerations
- special target groups
- the roles and responsibilities of policy makers
- education and prevention priorities
- effectiveness of existing strategies
- funding and research

A two-page questionnaire (see Part Two - Findings section) was developed and distributed to over 2,000 similar sources requesting descriptive information on existing aboriginal AIDS education and prevention programs and identification of program priorities. Over 200 completed questionnaires were received and the comprehensive results are available from the Federal Centre for AIDS on request.

All data and information were analyzed based on the research issues identified in the framework and additional issues were considered in relation to the implications for a National Strategy on Aboriginal AIDS Education and Prevention.

An Interim Report was developed by the Joint National Committee based on preliminary research and was released on June 26, 1989 for further public input into the

Strategy. The Interim Report generated interest in the Strategy from across Canada as evidenced by correspondence offering opinions and constructive criticism. All input was considered in the development of the Findings Document.

A first draft of the Findings Document was reviewed by the Joint National Committee in September and subsequent drafts (based on new information and revisions) were reviewed throughout October and November 1989 by members of the Executive Committee.

Exhibit 1

ABORIGINAL AIDS: EDUCATION AND PREVENTION STRATEGY

Research Framework

## ABORIGINAL AIDS: EDUCATION AND PREVENTION STRATEGY
### Research Framework

**HYPOTHESIS ONE:** The factors that lead to HIV infection and to the development of HIV spectrum disease and AIDS are present within the aboriginal community.

| ISSUES/QUESTIONS | DATA | DATA SOURCES | METHODS |
|---|---|---|---|
| 1.1 How many Aboriginal people are HIV infected and have AIDS?<br><br>Do these people share common characteristics and backgrounds? | - current known number<br>- socio-economic / demographic data | - Federal Centre for AIDS<br>- Informal interviews<br>- Interviews with PWA's<br>- Call for Papers | - statistical review<br>- survey<br>- interviews<br>- document review |
| 1.2 What are the factors that lead to HIV infection? | - AIDS epidemiology studies<br>- analysis of medical literature | - Federal Centre for AIDS<br>- Medical literature<br>- Call for Papers | - literature review<br>- statistical analysis<br>- document analysis |
| 1.3 What factors lead to the development of HIV spectrum diseases and AIDS? | - AIDS epidemiology studies<br>- analysis of medical literature | - Federal Centre for AIDS<br>- Medical literature<br>- Call for Papers | - literature review<br>- document analysis |
| 1.4 Are these factors present within the aboriginal population? | - review of factors and the presence in the aboriginal community as indicated by various medical and socio-economic studies | - Federal Centre for AIDS<br>- Call for Papers<br>- Interviews<br>- Available medical and anthropological literature and studies | - literature review<br>- document analysis |

## ABORIGINAL AIDS: EDUCATION AND PREVENTION STRATEGY
### Research Framework

**HYPOTHESIS TWO:** There is a need for Aboriginal-specific AIDS Education and Prevention programs and activities.

| ISSUES/QUESTIONS | DATA | DATA SOURCES | METHODS |
|---|---|---|---|
| 2.1 What Aboriginal organizations provide AIDS education and prevention programs? | - types of organizations<br>- types of activities<br>- how initiated, why initiated<br>- funding level, sources of funds<br>- sources of information for use in AIDS education programs | - Call for Papers<br>- Survey questionnaires<br>- Informal interviews with selected groups<br>- Literature/document review | - Data collection/analysis |
| 2.2 What results are these programs/activities demonstrating? | - evaluation<br>- observed behavioral modification<br>- level of knowledge about safe sex and other AIDS prevention measures | - Call for Papers<br>- Survey questionnaire<br>- Informal interviews with Aboriginal groups<br>- Literature/document review | - Data collection/analysis |
| 2.3 Do other organizations or service providers offer AIDS prevention and education programs specifically for Aboriginal people? | - how initiated, why initiated, priority?<br>- presence of AIDS education materials in schools<br>- presence of AIDS education material in Medical Services offices, etc. | - Call for Papers<br>- Survey questionnaires<br>- Informal interviews with Aboriginal groups<br>- Literature/document review | - Data collection/analysis |

## ABORIGINAL AIDS: EDUCATION AND PREVENTION STRATEGY
### Research Framework

**HYPOTHESIS TWO:** There is a need for Aboriginal-specific AIDS Education and Prevention programs and activities.

| ISSUES/QUESTIONS | DATA | DATA SOURCES | METHODS |
|---|---|---|---|
| 2.4 What types of activities/programs have the greatest impact on the Aboriginal community? | - evaluation results<br>- past experience with similar issues<br>- opinion of key informants | - Service/Information providers<br>- Aboriginal organizations<br>- PWA's<br>- Call for Papers<br>- Interviews/survey | - Data collection/ analysis |
| 2.5 Do Aboriginal people currently participate in any non-Aboriginal AIDS education and prevention programs? | - numbers of Aboriginal people served<br>- location of programs/ activities<br>- types of programs/activities | - Document/literature review<br>- Call for Papers<br>- Service/Information providers<br>- Informal discussions | - Data collection/ analysis |
| 2.6 What steps should First Nations, Aboriginal organizations, Provincial and Federal governments take in educating Aboriginal people about AIDS? | - evaluation<br>- proposals<br>- USA experience<br>- opinion of key informants | - Aboriginal organizations<br>- Document/literature review<br>- Service/information providers<br>- Informal discussions | - Data collection/ analysis |
| 2.7 Is AIDS education and prevention a priority in Aboriginal communities? | - level of interest<br>- level of funding, etc.<br>- statements by aboriginal leaders | - Call for Papers<br>- Aboriginal organizations | - Data collection/ analysis |

## Section Three: FINDINGS

**Part One**

Hypothesis One: The factors that lead to HIV infection and to the development of HIV spectrum diseases and AIDS are present within the aboriginal community.

Issue/Question 1.1: How many aboriginal people are HIV infected and have AIDS?

Do these people share common characteristics and backgrounds?

Findings:

1. **Presence of HIV in the aboriginal community.**

According to statistics available from the Federal Centre for AIDS (FCA), resulting from data collected by reporting physicians across the country through the AIDS surveillance process, there have been a total of twenty-two (22) AIDS cases among the aboriginal population as of November 23, 1989.

The following two charts indicate categories of transmission for the reported cases, first for the general Canadian population and, second for the aboriginal population.

**AIDS CASES IN CANADA**
**As of November 6, 1989**[1]

| 1. **Adult Cases** | Cases (%) |
|---|---|
| Homosexual/bisexual activity | 2489 (80.8) |
| Injection drug use | 29 (0.9) |
| Both of the above | 91 (3.0) |
| Recipient of blood/blood products | 157 (5.1) |
| Heterosexual Activity | |
| a) origins in endemic area | 135 (4.4) |
| b) sexual contact with person at risk | 88 (2.9) |
| c) no identified risk factors | 91 (3.0) |
| Sub-total | 3080 (100.0) |

| 2. **Paediatric Cases** | Cases (%) |
|---|---|
| Perinatal Transmission | 41 (82.0) |
| Recipient of Blood/Blood products | 9 (18.0) |
| Sub-total | 50 (100.0) |

| | |
|---|---|
| **TOTAL** | 3130 |

[1]Surveillance Update: AIDS in Canada, Federal Centre for AIDS, November 6, 1989.

**ABORIGINAL POPULATION AIDS CASES IN CANADA**
**As of November 23, 1989**[2]

| 1. **Adult Cases** | Cases (%) |
|---|---|
| Homosexual/bisexual activity | 15 (69) |
| Injection drug use | 1 (4) |
| Both of the above | 1 (4) |
| Recipient of blood/blood products | 2 (8) |
| Heterosexual Activity | |
| a) origins in endemic area | 0 (0) |
| b) sexual contact with person at risk | 2 (8) |
| c) no identified risk factors | 0 (0) |
| Sub-total | 21 (95) |

| 2. **Paediatric Cases** | Cases (%) |
|---|---|
| Perinatal Transmission | 1 (4) |
| Recipient of Blood/Blood products | 0 (0) |
| Sub-total | 1 (4) |
| **TOTAL** | 22 (100) |

[2]IBID, November 23, 1989.

The following chart compares reported aboriginal AIDS cases with those of other ethnic/racial groups in Canada and notes gender as well as categories of transmission or risk factors.

**AIDS IN CANADA**
**BY RACE/ETHNIC ORIGIN**
**GENDER AND RISK**
**November 23, 1989[3]**

| VARIABLE | ABORIGINAL | CAUCASIAN | BLACK | INDO ASIAN | HISPANIC | ORIENTAL | UNKNOWN | TOTAL % |
|---|---|---|---|---|---|---|---|---|
| I GENDER | | | | | | | | |
| MALE | 17 | 1732 | 138 | 17 | 19 | 7 | 1022 | 2950 (93.7%) |
| FEMALE | 5 | 91 | 70 | 2 | 0 | 1 | 29 | 198 (6.3%) |
| II Risk Factors | | | | | | | | |
| ADULTS: | | | | | | | | |
| Homosexual/Bisexual Activities (only) | 15 | 1519 | 24 | 11 | 17 | 6 | 914 | 2504 (79.5%) |
| Injection Drug User (only) | 1 | 16 | 3 | 0 | 1 | 0 | 8 | 29 (0.9%) |
| Both of Above | 1 | 54 | 2 | 2 | 0 | 0 | 32 | 91 (2.9%) |
| Recipient of Blood Products | 2 | 100 | 1 | 2 | 0 | 2 | 50 | 157 (5.0%) |
| Heterosexual Activity: | 0 | 0 | 131 | 0 | 0 | 0 | 4 | 135 (4.3%) |
| (a) origin in Pattern II country | 2 | 64 | 9 | 2 | 0 | 0 | 12 | 89 (2.5%) |
| (b) sexual contract with person at risk | 0 | 58 | 6 | 1 | 1 | 0 | 27 | 93 (2.9%) |
| Not identified Risk Factors | 1 | 6 | 32 | 1 | 0 | 0 | 1 | 41 (1.3%) |
| | 0 | 6 | 0 | 0 | 0 | 0 | 3 | 9 (0.3%) |
| PAEDIATRIC: | | | | | | | | |
| Prenatal Transmission | | | | | | | | |
| Recipient of Blood/Products | | | | | | | | |
| TOTAL: | 22 | 1823 | 208 | 19 | 19 | 8 | 151 | 3148 (100%) |

[3]Surveillance Update: AIDS in Canada, Federal Centre for AIDS, November 23, 1989.

Analysis of available data indicates that 75% of reported aboriginal AIDS cases are male compared to 93.7% in the general population. Further research indicates that 74% of reported aboriginal AIDS cases are between the ages of 20 to 35 years of age compared to 63% in the general population.

2. **Completeness of Data**

> The Interim Report of the Joint National Committee on Aboriginal AIDS Education and Prevention noted the following:
>
> Although no aboriginal AIDS cases have been officially reported in Manitoba, a recent informal interview with a Winnipeg-based street program worker revealed that a number of HIV infected individuals and AIDS cases exist among the aboriginal population of Winnipeg.[4]

A presentation by Bertha Blondin and Anne Thorpe at the First Canadian Conference on AIDS and Related Issues in the Native Community in Vancouver revealed the following:

> To date, there are six individuals who have been reported to be HIV positive including one diagnosis of AIDS. The case of AIDS was diagnosed in May 1987, and the first HIV seropositive case was reported in 1987.[5]

Although the degree of underreporting is unknown at this time, respondents to the questionnaire developed to guide the development of the National Strategy, indicated that there are many more cases of AIDS among the aboriginal population than is reported through the official system.

A paper submitted by the Nuu-chah-nulth Health Board of British Columbia supports the underreporting:

> At the end of 1988, the Nuu-chah-nulth Health Board received the first reliable information that a Nuu-chah-nulth male had tested HIV positive.

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[4] Joint National Committee on Aboriginal AIDS Education Prevention - Interim Report, June 26, 1998.

[5] Blondin and Thorpe, Syllabus: Programs: Northwest Territories, First Canadian Conference on AIDS and Related Issues in the Native Community, Vancouver, B.C., April 89.

> Due to medical confidentiality no name could be provided. Since that time we have been made aware of two other Nuu-chah-nulth cases. There are 3 cases in the local population of about 4,000. There are undoubtedly others among the membership who live away in one of the larger urban centres such as Vancouver.[6]

Underreporting of the numbers of Native American AIDS cases has been noted as a serious problem in the United States:

> Though the number of AIDS cases among Native Americans is relatively small, there are serious questions regarding the extent of underreporting. Even if the reported number of cases is viewed as accurate, there may be as many as 6,300 Indian people infected with HIV, unaware of the fact and capable of spreading the virus.[7]

Given the long incubation period of HIV, it is probable that many more aboriginal people are infected than show symptoms. Therefore, even based on the limited number of reported cases, there is genuine cause for alarm and a need for urgent response.

### 3. Characteristics of People With AIDS

Limited background information on those aboriginal people who are HIV positive and have AIDS is available, but more detail is required if the spread of the disease is to be effectively monitored and education and prevention programming is to meet the needs of the target audience. Data are needed specifically to:

(a) Monitor the progress of the disease,
(b) Plan effective prevention programs,
(c) Allocate resources, and
(d) Evaluate prevention programs.

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[6]Simon Read, A Native Health Organization Perspective on the Prevention of the Spread of AIDS, Nuu-chah-nulth Health Board, Port Alberni, B.C., July 89.

[7]Ron Rowell, Native Americans: Historic Problems Hamper AIDS Prevention and Care, NAN Multi-Cultrual Notes on AIDS Education and Service, Vol.1, No. 11, USA, May 1988.

An FCA survey of local and national AIDS organizations and members of Federal/Provincial/ Territorial Advisory Committee on AIDS indicated the following:

> Some basic demographic and epidemiological data needs remain, most important was the need for HIV seroprevalence information. This information was seen by several respondents as essential for program development and evaluation.[8]

A U.S. article on Women, AIDS and Public Policy noted the following:

> Even the American College of Obstetricians and Gynaecologists has shown some uneasiness, not because of the gender issue but because the women presently infected are primarily women of colour and, even more importantly, have intravenous drug use as a major risk factor.[9]

Seventy-four percent (74%) of reported aboriginal people with AIDS are between the ages of 20 to 35 years. This statistic is important when studying the potential impact of AIDS on aboriginal communities. The World Health Organization (WHO) noted the following:

> However, the major social impact of AIDS worldwide is the direct result of the dominant role of sexual transmission of HIV. Thus, the brunt of illness and death is currently borne by 20- to 49-year-olds. In contrast to many public health problems which selectively affect either the very young or the old, AIDS affects the segment of the population that is the most vital in terms of social and economic development. The selective involvement of young and middle-aged adults--including business and government cadres and members of social, economic, and political elites--leads to potential for economic and political destabilization in areas of the developing world most severely affected by HIV. What political

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[8]Kathleen O'Malley, Preliminary Report on a Survey...On Key Issues and Information Required for Programming Strategies to Prevent the Sexual Transmission of HIV, Federal Centre for AIDS, Health and Welfare Canada, July 10, 1989.

[9]Janet L. Mitchell, Women, AIDS and Public Policy, USA, 88.

> system could withstand the ultimate destabilizing impact of a 20 or 25 percent or higher HIV infection rate among young adults?[10]

An American article on Intravenous Drug Abuse and AIDS in Minorities makes a similar point:

> As important as AIDS and HIV-related morbidity and mortality data are, still other dimensions of the epidemic are often unappreciated. IVDAs [Intravenous Drug Abusers] and ethnic/racial minorities are often concentrated in urban, economically disenfranchised areas. How can these communities, which already lack adequate human and health care resources, accommodate increases in the demands for these services? These new demands emanate from a sector of the communities--namely, those aged 20 to 40--who, prior to the epidemic, were infrequent consumers of human and health care services. This age range includes the most productive years of life. Thus, the further erosion of the economic base of black and Hispanic communities due to the unavailability of an important component of the work force is another potential consequence for the HIV epidemic.[11]

A Manitoba HIV Seroprevalence study drew the following comparisons between aboriginal people at risk of acquiring HIV and others at risk:

> The mean age of Native and Metis were significantly lower for both males ($p<0.04$) and females ($p<0.0001$) vs. Caucasian and other races. A disproportionately large number of Native/Metis were enroled from the risk category of sexually transmitted diseases ($p<0.001$)(Yates corrected $X^2$), but significantly fewer Native/Metis were enroled from the category of sex contact with a person at risk ($p<0.0001$, Fisher's exact test). Native Indian and Metis had significantly lower education levels($p<0.001$ by the Maentel-Haenszel

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[10]Jonathan Mann, AIDS Epidemiology, Impact, Prevention and Control: The World Health Organization Perspective, WHO, 88.

[11]Brown and Primm, Intravenous Drug Abuse and AIDS in Minorities, U.S.A., 88.

test for trends, $X^2$ = 46.8) and higher unemployment levels ($p<0.001$ by the $X^2$ test, $X^2$ = 42.4).[12]

This analysis is important in that it points out (in this case) that the aboriginal participants in the study were significantly younger than others, had higher STD rates, less contact with persons at risk, lower education levels and higher unemployment levels. Demographic information (such as age, education level and employment status) is an essential consideration in designing effective prevention messages. Data relating to higher STD rates and less contact with persons at risk may indicate a significantly different pattern of HIV transmission than mainstream Canadian society. The fact that this group of aboriginal participants had less contact with persons at risk may indicate that HIV was transmitted through heterosexual activity with an infected person.

Finally, the literature points out that it is estimated that for every individual with AIDS, there are between 50 and 100 people who are HIV positive. Based on reported AIDS cases in the aboriginal population this would mean that there are between 750 and 1500 aboriginal people who are HIV positive.

Conclusion

While available FCA statistics on the number of aboriginal people who are HIV infected and have AIDS is underestimated, it is clear that AIDS exists and is increasing in the aboriginal community.

Preventative measures are urgently required since the presence of AIDS indicates that HIV infection has already taken a foothold.

Because data is incomplete, steps should be taken to correct the situation. Generally, HIV Seroprevalence information and demographic data is lacking and is essential for:

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[12]G.W. Hammand, et al, Seroprevalence and Demographic Information of Patients at Risk for Human immunodeficiency Virus (HIV) in Manitoba, Canada, Journal of Acquired Immune Deficiency Syndromes, Raven Press, New York, 88.

(1) Monitoring the spread of the disease
(2) Program Planning
(3) Resource allocation
(4) Program Evaluation

The literature indicates that the majority of aboriginal people with AIDS or who are at risk of acquiring HIV are between the ages of 20 and 35 years, have higher STD (sexually transmitted disease) rates, have significantly lower education levels and higher unemployment levels than a similar sample of Canadians and other ethnic groups.

For the known AIDS cases (officially reported) the risk pattern is similar to the mainstream North American epidemic, however, high STD rates and its resultant affect on the immune system may increase the expression of HIV diseases among aboriginal heterosexuals once infected.

Issue/Question 1.2: What are the factors that lead to HIV infection?

Findings:

1. **Factors**

There are four broad categories for the transmission of HIV as follows:

(1) Unprotected sexual activity - i.e.,
- unprotected anal intercourse
- unprotected vaginal intercourse

(2) Needle sharing - i.e.,
- the practice of sharing needles for use in injecting illegal drugs

(3) Perinatal transmission - i.e.,
- HIV from mother to child before, during and after birth.

(4) Other (these represent a minimal threat) - ie.

- blood transfusions
- occupational exposure
- cultural specific/ritual practices

2. **Presence within aboriginal communities**

Of the twenty-two (22) FCA reported cases of AIDS in the aboriginal population, the stated risk factors were reported to be:

15 acquired AIDS through homosexual/bisexual activity,

1 acquired AIDS through injection drug use,

1 acquired AIDS through both of the above,

2 acquired AIDS through heterosexual contact with person at risk,

1 acquired AIDS through a perinatal/paediatric case.

Data from the US Centre for Disease Control on Native Americans with AIDS in the United States indicates a similar pattern in that, out of a total of one hundred and four (104) reported cases, fifty-four (54) or 51% of the total

> resulted from participation in homosexual or bisexual activities, seventeen (17) cases or 16% resulted from intravenous drug use and fourteen (14) cases or 13% resulted from a combination of homosexual/ bisexual activity and intravenous drug abuse.[13]

In terms of the four broad categories for the transmission of HIV, unprotected sexual activity in aboriginal communities is evidenced by high STD rates, the growing number of teenage pregnancies and generally high birth rates. High STD rates not only indicate the prevalence of unprotected sex but, inflammation in the genital area caused by many STDs has been shown to increase the efficiency of the transmission of HIV. Unprotected anal intercourse among aboriginal men is evidenced by the ten reported AIDS cases identifying homosexual/bisexual activity as the risk factor.

While there is limited documentation on needle-sharing in the aboriginal community, the Downtown Eastside Youth Activities Society (DEYAS) Needle Exchange Program in Vancouver, B.C. keeps statistics by ethnicity and reports that approximately 40% of individuals utilizing the needle exchange program in that city are aboriginal. An additional consideration in needle-sharing is that while the individual who participates in this high risk behaviour and who has unprotected sex with a partner (heterosexual or homosexual) may transmit the virus acquired through injecting drugs.

Perinatal transmission is often linked to HIV through needle-sharing.

The general category of "Other" presents minimal risks in that the blood used for transfusions, for example, is now tested for AIDS antibodies and occupational exposure (lab technicians, ambulance service workers, etc.) has been minimalized by education and prevention measures. However, it is unknown to what degree cultural specific/ritual practices may impact the spread of HIV in aboriginal communities.

### 3. Health Factors

It is important to consider the general health of the population when studying the potential impact of HIV. There is evidence to suggest that an individual with an immune system that has been "overactive" in fighting off

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[13]Federal Centre for AIDS Statistics, May 23, 1989.

a variety of illnesses (i.e., STDs) or is depleted by other chronic diseases (i.e., diabetes), may experience a more rapid expression of the disease after becoming infected with HIV.

> Canadian Indians living on reserves have high mortality and morbidity rates. Their life expectancy is 10 years less than the national average. The infant mortality rate is 60% higher and postnatal mortality rate 100% higher than the national figures. The incidence of suicide is much higher in native youth than in any comparable group. Canadian Indians also have a high incidence of major causes of disability, such as anaemia, diabetes, gallbladder disease, infectious and parasitic diseases, lung disease, hearing impairment, visual defects and dental problems. Mental health disorders and problems resulting from drug and alcohol abuse are also prevalent. The proportion of disabled and handicapped native people is higher than in any other segment of the Canadian population.[14]

A similar situation exists in Australia with the aboriginal people there:

> Over the last few decades, the Aboriginal Infant Mortality Rate (IMR) has improved, but it is still 3-4 times that of non-Aboriginal children. This improvement has been achieved mainly through increased access to appropriate primary care in acute situations. However, the IMR has been fairly static since 1979-80. Further improvement will require political and social change that addresses the continuing socio-economic disadvantage of Aboriginal people.[15]

4. <u>Access to health information</u>

The poor health status of the aboriginal population of Canada not only reflects socio-economic and political disadvantage but lack of access to relevant health

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[14]Shah and Farkes, <u>The Health of Indians in Canadian Cities: A challenge to the Health Care System</u>, Canadian Medical Association, Vol. 133, November 1, 85.

[15]Department of Community Services and Health, <u>Report of the Working Panel on Aboriginals, Torres Strait Islanders and HIV/AIDS</u>, Commonwealth of Australia, 89.

information and services. These factors may increase the risk of aboriginal people becoming infected with HIV.

Mainstream Canadian society receives health information largely through television Public Service Announcements and the print media. Remote and isolated aboriginal communities do not have equal access to this information via television and the literary levels of the aboriginal community makes the impact of available printed materials questionable.

The FCA's Preliminary Report on Key Issues and Information Required for AIDS Programming Strategies noted the following:

> Natives are at special risk for a variety of reasons; they mistrust government and western medicine; they view AIDS as a 'white man's disease'; they have few appropriate materials. (B.C. Ministry of Health)[16]

5. **Discrimination**

An informal interview with a homosexual Native in Toronto revealed that he had been discriminated against by a non-aboriginal homosexual organization when he sought basic information about preventing HIV infection.

A 1988 American publication compiled by Gay American Indians (GAI) noted the following:

> As Indians, our cultural and economic survival is threatened by poverty, poor education, and unemployment. Many American Indians have left reservations for urban areas (where nearly 50 percent of Indians live today). But in the cities, we find racial prejudice, discrimination, and denial of education, job training, employment, and housing.
>
> In fact, racial discrimination is not limited to the nongay community. In 1983 GAI participated in hearings sponsored by the San Francisco Human Rights Commission that documented discrimination against nonwhite people within the lesbian/gay community itself. Even now, leadership roles in

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[16]Kathleen O'Malley, Preliminary Report on a Survey...On Key Issues and Information Required for Programming Strategies to Prevent the Sexual Transmission of HIV, Federal Centre for AIDS, Health and Welfare Canada, July 10, 1989.

the gay community continue to be filled by white males, and minority tokenism is the rule.

Organizations are always coming to GAI, eager for Indian representation--but they fail to address the economic and social obstacles to equal and full participation, and they ignore our input when we do participate.[17]

6. **Alcohol abuse**

In the USA and in Canada, alcoholism amongst the aboriginal population is a serious social issue. The National Native American AIDS Prevention Center, in an AIDS manual prepared for Native American Health and Human Service Workers made the following points:

Most of us are aware that alcoholism is responsible for most of the top ten causes of death for Native people. In each of our communities, we know of friends, family members, sons and daughters, mothers and fathers, whose lives are affected by alcohol.

Although alcohol per se is not involved in the transmission of the virus, use of alcohol may play a role in behaviours that do transmit AIDS.

Studies have shown that the use of alcohol and other drugs is positively associated with high-risk sexual behaviour. Those who abstained from alcohol and other drugs during sex were found not to have engaged in high-risk sexual behaviour. Those who combined sex with alcohol and drug use were most likely to have had a history of high-risk sexual behaviour over the previous year.

Other researchers studying alcoholism and high-risk behaviour have suggested that early diagnosis and treatment of depression and substance abuse in homosexual men may help to prevent the spread of AIDS. Use of alcohol was found to result in risk-taking, lack of inhibition, and self-destructiveness. In one study, three men in New

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[17]Roscoe, Living the Spirit - A Gay American Indian Anthology, St. Martins Press, USA, 1988.

York who were in alcoholism treatment had consciously attempted to contract AIDS as a form of suicide.[18]

**High Risk Behaviours and Specific Groups Within the Aboriginal Population:**

The research indicated that some groups within the aboriginal community more than others may be at risk of becoming infected with HIV due to high risk behaviours (i.e., IV drug users) or other circumstances (i.e., aboriginal children).

**Aboriginal Homosexual and Bisexual Population**

Unsafe sexual activities by aboriginal men have resulted in 13 reported cases of AIDS out of a total of 20 for the aboriginal population. While many aboriginal people continue to deny the existence of homosexuals, bisexuals and lesbians within their population, the emergence of four aboriginal gay and lesbian organizations across the country dispute this claim.

While unsafe sexual activities amongst homosexuals and bisexuals pose a serious threat to acquiring HIV infection within this group, the fact that many aboriginal people must hide their sexuality, especially from their own communities due to misconceptions and prejudices, may lead to "living a double life". The following illustrates this point:

Some homosexual/bisexual people live open lives 'out of the closet.' Others lead disguised lives, either as singles or as married partners with families. Many reservation Indians may lead double lives, one in the city and one 'back home.' Some reservation people may be unaware that there actually are gay or bisexual tribal members. For some tribes, a relationship between two men or two women that does not impair their functioning within an extended family unit is not considered threatening. Traditionally, many tribes (though not all) had a concept of three or four genders, with a social role available for 'sexual minorities.' With the establishment of reservations based on the missionary/superintendent model, homophobia (fear of gay

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[18]Ron Rowell, Acquired Immune Deficiency Syndrome: The basics, A Manual for Native American Health and Human Service Workers, National Native American AIDS Prevention Centre, Oakland, California, USA, 87.

people) replaced what for some tribes were far more liberal and accepting attitudes. As a result, some tribal members have no living memory of a different attitude towards same sex relationships.

For those people who are 'in the closet', an AIDS diagnosis can be doubly devastating by bringing to light a sexual orientation with which they have never come to terms. Parents learn of their child's terminal illness at the same time they learn their child is homosexual. Wives discover their husband's extramarital homosexual affairs. Guilt, shame and self-condemnation can be the result.[19]

The leading of a "double life" may present a threat to the heterosexual partners of closeted aboriginal bisexuals. There is evidence to suggest that aboriginal males participate in unsafe bisexual activities as a result of alcohol abuse.

A Montana report suggests the following:

> We do not have accurate data concerning the prevalence of homosexual and bisexual behaviour on Montana Indian reservations. However, experience suggests that homosexual and bisexual behaviour is practised and that anal intercourse occurs among severely intoxicated males. Bisexuality may be more common than homosexuality. This is of special concern because it places women and unborn children at increased risk of infection.[20]

Available data from the FCA clearly indicate that unsafe homosexual and/or bisexual activity accounts for the greatest risk factor in contracting AIDS. However, it is important to note the following:

> It is important to note the contribution made by Gay and Lesbian Natives: it is our understanding that Native North American Gay and Lesbian groups exist in Canada, with one being in Toronto; and that Gay and Lesbian Natives (although perhaps closeted) have been involved in raising awareness

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[19]Ron Rowell, Acquired Immune Deficiency Syndrome: The Basics. A Manual for Native American Health and Human Service Workers, National Native American AIDS Prevention Center, Oakland, California, USA, 87.

[20]John J. Drynan, AIDS and Native American In Montana, Centers for Disease Control, Atlanta, Georgia, USA, 88.

of the impact of HIV infection/AIDS among their people.

> There is sufficient data to show that the non-Native Gay and Lesbian community has been in the forefront in fighting the war against AIDS through educational work in their own community and outside of the Gay and Lesbian community; therefore it is important to cite and recognize this fact.[21]

**Injection Drug Users**

The extent to which Canadian aboriginal people inject illicit drugs is unknown. Injection drug use has resulted in one reported case of AIDS amongst the aboriginal population and one more where a combination of injection drug use and homosexual/bisexual activity was cited as the means of transmission. While unsafe homosexual and/or bisexual activities have resulted in the largest number of reported AIDS cases within the aboriginal population, there is a fear that substance abuse, specifically injection drug use, will emerge as a significant contributor to the spread of HIV in the near future.

Native Americans have recognized the significant threat that injection drug use poses:

> Most of the top 10 causes of death among Native Americans are related to extremely high rates of alcoholism and substance abuse. More than one-third of all Indian people die before the age 45 from diseases directly related to alcohol and substance abuse.
>
> The Indian health care system has focused exclusively on the alcohol problem without monitoring and analyzing possible changes in patterns of abuse, especially among younger Indian people. Again, anecdotal evidence from residents and providers in California Indian alcoholism treatment programs as well as among tribal leaders appears to indicate that growing numbers of Indian youth are shooting drugs, especially amphetamines, intravenously. A related issue raised by tribal leaders is that syringes and needles used by

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[21]Farkas and Kossman, Central Toronto Youth Services AIDS Project Reaction to the Interim Report of the Joint National Committee on Aboriginal AIDS, Toronto, 89.

> diabetics-also a serious health problem for Indian people-are being shared by household members to inject drugs.[22]
>
> Sharing needles is one of the most effective ways of infecting others or becoming infected. However, the use of drugs even when no needles are shared can result in types of behaviour that place a person at high risk for HIV infection. Therefore, early intervention to help people stop abusing drugs can also help to stop the spread of AIDS.[23]

There is evidence to suggest that members of minority groups, i.e., aboriginal people, injecting illicit drugs tend to segregate themselves from other groups injecting drugs. This may be due to mistrust of potential non-aboriginal informants and fear of retaliation, but the fact that this high risk group may remain relatively isolated, even within large urban centres, gives some hope for the success of aboriginal-specific prevention programs.

**Aboriginal Youth**

Aboriginal youth are perceived as at a high risk of acquiring HIV infection because they are sexually active and often unprotected as evidenced by the high number of teenage pregnancies; they are under the strain of peer pressure to use and abuse alcohol and a variety of substances; some have been sexually abused; some are homeless, transient and street dwellers.

Glen Murray, Director of the Village Clinic in Winnipeg in a presentation to the Joint National Committee on Aboriginal AIDS Education and Prevention described the following situation:

> Native youth in Manitoba appear to be at increased risk for contracting AIDS because of high rates of sexually transmitted diseases amongst the population; part of the street culture, use

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[22]Ron Rowell, Native Americans: Historic Problems Hamper AIDS Prevention and Care, NAN Multi-cultural Notes on AIDS Education and Service, Vol.1, No. 11, May 88.

[23]Ron Rowell, Acquired Immune Deficiency Syndrome: The Basics, A Manual for Native American Health and Human Service Workers, National Native American AIDS Prevention Center, Oakland, California, USA, 87.

> injection drugs; are the least educated; suffer from systemic racism; lack access to health care and often are in conflict with the law; come from dysfunctional families or are rejected by their families; lack income and engage in sex for survival; poor physical health and malnutrition; lack of youth support systems.[24]

Mr. Murray, who is actively involved with street youth in the city of Winnipeg described the vulnerability of aboriginal youth from a professional, objective and knowledgeable perspective:

> When you look at the intersection of youth and Native people...if you look at the next 500 or 1000 people who are going to be infected in this province, a disproportionate large number will be IV drug users and street youth, of which a huge percentage are aboriginal young people. They have the least education, suffer inherent systemic racism in the health care system and are often in conflict with the law. They come into large urban centres with positive and open values that they have developed in smaller communities where they know their neighbours and have a sense of heritage, trust and openness. When they get into a city and drugs are given to them free...they get Talwin and Ritalin... The same thing happens with women in a large centre who are marginalized simply because they are women.
>
> There is something I call the HIV continuum which people get on. If you are looking at youth and you have a young person who has no economic means...perhaps there is sexual abuse in the home or other barriers in the home. A young woman who has become sexually active before her parents want her to and is rejected by her family. A young man who identifies himself as gay and is rejected by the family and ends up on the streets. They all go to find places to live. They walk around the downtown core area of the city and they stay in crash houses. Most often they sleep with someone for the night and have sex. If they are low income...many of them don't have a job and working at McDonald's isn't the kind of income that most kids can live on...or if they've come into a large

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[24]Summary of Glen Murray's Presentation to the Joint National Committee on Aboriginal AIDS Education and Prevention, Winnipeg, Manitoba, May 28 - 30, 89 (from Meeting Minutes).

urban school and haven't been successful...they often won't feel comfortable back home. They end up in situations where they get involved in prostitution for money or even break and entering. They often get in conflict with the law, social services, health care and the legal system...all of which presents a whole set of risks to them.

A lot of kids get hit-up for a lot of soft drugs...get involved in alcohol and alcoholism. Once they are shooting-up, they are shooting-up 6-10 times a day...going through $1,000 a day habits. We have hundreds of kids on the city streets in that situation. Once they get into that, their sexual activity level and their IV drug use habits present a whole lot of problems, as does their general health situation. Most of them suffer from malnutrition. Many are not eating well...living on chocolate bars, chips and a coke, maybe McDonald's once in a while. Needle use gives them another route to infection. Talwin and Ritalin gives them another as does their sexual activity. They are open to many very direct routes of infection.

High levels of sexual activity related to their survival. Some find emotional satisfaction and gratification through sex in the absence of affection. They feel alienated. Poor physical health due to malnutrition and the use of Talwin and Ritalin take their toll on the immune system. It lowers their lymphocyte levels. It makes the body more vulnerable to disease. Often they will get a sexually transmitted disease...something like chlamydia which 80% of the time is not symptomatic. The mucous membranes inside the vagina, rectum or penis becomes inflamed. During sexual intercourse, any breakage of the tissue gives you a higher chance of infection. Some people would argue, it's a requirement for infection. It is unusual for me not to see someone who has herpes...although it is not reportable in the province...or blistering which aids in infection.[25]

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[25]Glen Murray's Presentation to the Joint National Committee on Aboriginal AIDS Education and Prevention, Winnipeg, Manitoba, May 28 - 30, 89 (verbatim transcript).

HIV infection poses a serious threat to aboriginal youth living in rural, remote and reserve communities as well. While no specific data are available on the threat to this population exclusively, the scope of the problem related to children and AIDS in Canada generally was described in the following 1989 paper:

> HIV poses a double threat to adolescents. First, HIV infection is linked to risk-taking behaviours in areas of frequent adolescent experimentation: sex, alcohol, and drugs. Second, because few adolescents have yet become sick with AIDS, HIV remains an invisible threat that teenagers - with their youthful sense of vulnerability - often ignore or dismiss. Preliminary findings from new studies point to a growing incidence of HIV infection among adolescents.
>
> The steady rate of unwanted teenage pregnancies and the growing rate of sexually transmitted diseases (especially gonorrhoea and chlamydia among young women) suggests that HIV may spread through the adolescent population almost as quickly as it has in the gay population.
>
> In a recent survey of Canadian youth ("Canada Youth and AIDS Study", King et al, Queen's University, 1988), only 14% of sexually active young people reported consistently using condoms; more than one quarter had never used a condom. Approximately 15% of school drop-outs and college-aged youth in the study had experienced anal intercourse.[26]

Aboriginal youth will require special, innovative, and believable messages if the threat of HIV infection is to be controlled. Alternatives to unsafe sex, alcohol abuse and drug use must be acceptable and satisfying to this segment of the aboriginal population.

**People with AIDS**

As an example, Lee et al reported on an outbreak of infectious syphilis in Manitoba in 1984. "The case rate for native Indians was 21.7 per 100,000 population

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[26]Farkas and Kossman, Impact of HIV Infection on Social Service Agencies Serving Children and Youth in the Metro Toronto Area, Central Toronto Youth Services AIDS Report, Toronto, Spring 89.

compared with 6.6 per 100,000 for the non-native populations."[27]

The following knowledgeable opinion on sexually transmitted diseases resulted from the "Call for Papers" on Aboriginal AIDS Education and Prevention.

> Aboriginal communities are recognized as being potentially at high risk for the spread of human Immunodeficiency Virus Type 1 (HIV-1 or AIDS virus) because of the high reported rates of other sexually transmitted diseases (STD's) in these communities...
>
> Consider AIDS in the Context of Other STD's
>
> - although IV drug use and blood transfusions are also ways the disease can spread, the sexual route will be the main means of spread
>
> - people are already familiar with other STD's (Gonorrhoea, Chlamydia, etc.) and they may be able to relate to information on diseases which are familiar to them
>
> - there is increasing evidence that other STD's may enhance the spread of HIV within a community. Conversely, prompt recognition and treatment of other STD's may decrease the efficiency of HIV spread. Therefore, facilities and programs for treating and tracing STD's must be adequate.[28]

Glen Murray of the Village Centre Clinic in Winnipeg pointed out the following:

> When you look at Manitoba and you recognize that HIV follows in the footsteps of other sexually transmitted diseases, what you find is that 70% of

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[27]Health and Welfare Canada, Health Status of Canadian Indians and Inuit: Update 1987, MSB, Ottawa, 88.

[28]Dr. Michael Moffatt, et al AIDS Education and Prevention in Aboriginal Communities, University of Manitoba, Faculty of Medicine, Winnipeg, August 4, '89.

> STD's fall in the age group between 11 and 24 years old. This is mostly chlamydia and gonorrhoea.[29]

The literature revealed that Native Americans and the aboriginal population of Australia generally have higher STD rates than others living in their states and countries.

An Australian report noted the following:

> There is concern that where STD's are common, especially those causing genital sores and ulcers, then HIV infection may more readily occur on sexual contact with an infected partner.[30]

It is clear that people with STD's are at a high risk of being HIV infected due to their apparent unsafe sexual practices and the potential for infection through open genital sores resulting from certain STD's.

**Male and Female Prostitutes**

Very little information specifically dealing with aboriginal prostitution and high risk behaviour is available. It is clear from what is known about aboriginal street youth that prostitution has become a means of survival for many. Unsafe sexual activities are no doubt practised by adolescents on the street in exchange for money to buy drugs, food and temporary shelter.

In terms of "professional" aboriginal prostitutes, their activities may be compared to others engaged in prostitution:

> Prostitutes use condoms with customers (90%) but not lovers (18%). The connection between needle acquisition and sexual transmission is not always appreciated. Many women get infected from

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[29]Glen Murray, Presentation to the Joint National Committee on Aboriginal AIDS Education and Prevention, Winnipeg, Manitoba, May 28 - 30, '89 (verbatim transcript)

[30]Department of Community Services and Health, Report of the Working Panel on Aboriginals, Torres Strait Islanders and HIV/AIDS, Commonwealth of Australia, 89

'closeted' IV drug users and bisexuals. (B.C. Ministry of Health)[31]

The other issue that must be considered is the extent to which the services of prostitutes are used by aboriginal men travelling to the cities. A group of physicians from the University of Manitoba, Faculty of Medicine, noted the following:

> Program planners will need to have accurate information on some sensitive issues about risk factors. To mention a few:
>
> ...the frequency of use of prostitutes by men who travel from aboriginal communities.
>
> These seem to be the most likely ways that HIV infection could be introduced into aboriginal communities and accurate information on their prevalence is needed.[32]

**Aboriginal Women**

Aboriginal women may be at risk of contracting HIV from their sexual partner if they are unaware of activities practised outside of their relationship. Activities such as utilizing the services of a prostitute or "closeted" homosexual activities and injection drug use by men who are perceived to be monogamous and drug-free pose a threat to their sexual partners and unborn children.

In addition, many aboriginal women feel a lack of power in a sexual relationship as follows:

> The issues for women are not so much lack of information, but low self-esteem and a subsequent lack of assertiveness. This is particularly true for young adolescent women. Even when they fear getting AIDS, they can not visualize discussing safer-sex with a partner, and fear abandonment or possible violence if they insist on condom use. Work needs to be done in the schools around self-

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[31]Kathleen O'Malley, Preliminary Report on a Survey...On Key Issues and Information Required for Programming Strategies to Prevent the Sexual Transmission of HIV, Federal Centre for AIDS, Health and Welfare Canada, July 10, 1989.

[32]Dr. Michael Moffatt, et al AIDS Education and Prevention in Aboriginal Communities, University of Manitoba, Faculty of Medicine, Winnipeg, Manitoba, August 4, 1989.

esteem; and developing positive body images and self-care. (AIDS Saskatoon)[33]

**Aboriginal Children**

The threat of HIV infection to unborn aboriginal children through perinatal transmission is evident in that, to date, one reported case of AIDS has resulted from this form of transmission.

Sexual abuse of children in aboriginal communities is of growing concern. While accurate data on the prevalence of child sexual abuse in aboriginal communities is not available, the following comment from a Vancouver article, Children of the Street, should be noted.

> Turvey says sexual abuse is one of the main factors behind child prostitution on the streets of Vancouver. He believes 70% of the working children are native Indians from all parts of Canada. (Vancouver Sun, October 24, 1988)

The impact that sexual abuse of aboriginal children will have on the spread of HIV in aboriginal communities requires careful study.

**Aboriginal Prison Population**

No specific information on drug use or the sexual activities of aboriginal people in prison could be found. Cate Hankins presented the following perspective at the First Canadian Conference on AIDS and Related Issues in the Native Community, in Vancouver:

> Aboriginal people are over-represented as inmates and under-represented as employees in the Canadian correctional system. Aboriginal people comprise 2.5 per cent of the Canadian population but 9.6 per cent of federally incarcerated inmates and 1.2 per cent of federal corrections employees. Aboriginal women comprise 14.2 per cent of Canadian women in federal penitentiaries (1987). In addition to being over-represented as inmates, aboriginal people in prison serve a greater proportion of their sentences in prison. The issue of AIDS and HIV infection in prison settings

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[33]Kathleen O'Malley, Preliminary Report on a Survey...On Key Issues and Information Required for Programming Strategies to Prevent the Sexual Transmission of HIV, Federal Centre for AIDS, Health and Welfare Canada, July 10, 1989.

is therefore of particular interest to aboriginal communities in Canada...

In conclusion, it is clear that HIV infection and AIDS poses a problem in the correctional system of Canada. Small strides have been made in some areas in developing educational programmes for both guards and prisoners, but the basic environmental conditions in which risk behaviour can occur have not been modified. Condoms are not accessible, bleach is not necessarily available for the cleaning of needles, lighting has not been changed, there is no systematic approach to isolating vulnerable from more aggressive prisoners - much work need to be done...

Aboriginal inmates require specialized educational programs in the same way that aboriginal communities on the outside require and want culturally appropriate programs.[34]

## Other factors which may impact the aboriginal population

### Patterns of AIDS

In a 1988 Scientific American article, Jonathan Mann explains the patterns of AIDS as follows:

> Pattern I is typical of industrialized countries with large numbers of reported AIDS cases. The countries include the U.S., Mexico, and Canada...In Pattern I countries HIV probably began to spread extensively in the late 1970's. Most cases occur among homosexual or bisexual males and urban intravenous (IV) drug users. Heterosexual transmission is responsible for only a small number of cases.
>
> Because relatively few women are infected in these areas, to date perinatal transmission (transmission from mother to infant) is not common.
>
> Pattern II is presently observed in some areas of central, eastern and southern Africa and increasingly in Latin American countries particularly those of the Caribbean.

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[34]Cate Hankins, Syllabus: AIDS and Native in Corrections, First Canadian Conference on AIDS and Related Issues in the Native Community, April 89, Vancouver, B.C.

> ...most cases in Pattern II areas occur among heterosexuals and the ratio of infected males to females is approximately one to one. Transmission through homosexual activity or IV drug use is either absent of at a very low level but because many women are infected, perinatal transmission is common.
>
> Pattern III prevails in areas of Eastern Europe, North Africa, the Middle East, Asia and most of the Pacific...HIV was probably introduced in the early to mid-1980's and only a small number of AIDS cases has so far been reported. These have generally occurred in people who have travelled to Pattern I or Pattern II areas and who have had sexual contact with individuals from such areas.[35]

Although 65% of current reported cases of AIDS among aboriginal people have been reported as being acquired through homosexual or bisexual activity as in Pattern I countries including Canada, the factors outlined as contributing to AIDS in Pattern II countries (heterosexual transmission) are significantly similar to factors existing in the aboriginal population.

> HIV appears to be governed by the probability of exposure to an infected partner as well as the specific sexual acts performed with that partner. Although systematic studies of sexual behaviour in sub-Saharan Africa are not yet available, investigators have generally reported a greater number of sexual partners and/or contacts with female prostitutes among African males who have AIDS than among control groups. High rates of partner exchange, or the frequent exposure to a relatively small number of prostitutes of many men who then return to their spouses, could contribute to the epidemiological pattern of HIV infection in these areas. Among sexual practices, available studies strongly suggest that vaginal intercourse is the dominant behaviour in sub-Saharan Africa, reinforcing the supposition that frequency of sexual contact is the primary factor governing the transmission of HIV there.
>
> Certain aggravating factors may help to explain possible differences in susceptibility to HIV infection. For example, individuals whose immune

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[35]Jonathan Mann, et al The International Epidemiology of AIDS, Scientific American, October 1988, USA.

> system has been activated by chronic infections might be more easily infected on exposure to HIV. There is also increasing evidence that the presence of other sexually transmitted diseases increases the risk of HIV infection. Studies in Africa indicate that such diseases (in particular those characterized by genital ulceration, such as chancroid and syphilis) may increase susceptibility to infection on exposure to a partner carrying HIV or may increase the infectivity of a person carrying HIV. Studies in the U.S. show that HIV infection is positively correlated with the presence of genital or anal lesions in homosexual men. Moreover, the higher prevalence of sexually transmitted diseases, including chancroid and syphilis, in tropical Africa compared with general populations in Europe is consistent with the hypothesis that such diseases aggravate the spread of AIDS in Africa.[36]

In Pattern II countries, epidemiologists have speculated that HIV is spread through heterosexual transmission may be attributable to the numbers of sexual partners, the prevalence of sexually transmitted diseases and the negative impact STDs have on the immune system.

The literature points out that the aboriginal community in Canada has STD rates far exceeding that of the mainstream:

> As an example, Lee et al reported on an outbreak of infectious syphilis in Manitoba in 1984. "The case rate for native Indians was 21.7 per 100,000 population compared with 6.6 per 100,000 for the non-native populations".[37]

The threat of AIDS becoming increasingly prevalent among the heterosexual aboriginal population is important for the National Strategy on Aboriginal AIDS Education and Prevention. Canada is considered a Pattern I country and therefore, designs prevention messages and programs targeted specifically for groups who may engage in high risk behaviours. The message for the aboriginal community with the potential of becoming a Pattern II

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[36]Jonathan Mann, et al The International Epidemiology of AIDS, Scientific American, October 1988, USA.

[37]Health and Welfare Canada, Health Status of Canadian Indians and Inuit: Update 1987, MSB, Ottawa, 1988.

population within a Pattern I country is much broader and more complex in that it requires a thorough understanding of the sexuality of the various aboriginal cultures.

It is essential that a grasp of why STD rates are higher in aboriginal communities than in others within Canada if an AIDS prevention message is to be successful in achieving sustained behavioral change.

The literature review did not provide any insight into the views of aboriginal people on sexuality other than the dated interpretations of nineteenth century missionaries.

It is also clear from the description provided by Jonathan Mann's article in Scientific American that in Pattern III countries, HIV is likely introduced by people who have travelled in Pattern I or II areas, had sexual contact with infected individuals there and have returned to introduce HIV to others.

Aboriginal people travel out of their communities and return for a variety of reasons as expressed by the National Association of Friendship Centres in their 1989 presentation to the Joint National Committee on Aboriginal AIDS Education and Prevention:

> Our people move to the cities from the reserves and rural communities for a large number of reasons. They come to complete their education, find jobs, seek medical help, to escape strained home environment and so on...
>
> They retain their contacts with home, be that the reserve or rural community of birth or where their relations live and visit home regularly...
>
> The urban population is a highly mobile population travelling frequently from the cities to the reserves and back throughout the year. They are also a young people with a high fertility rate experiencing what can only be called a baby boom...
>
> We know that our people engage in sexual activity with others who engage in risk activities without using a condom. We also know that those at risk and those that have been exposed are travelling

back and forth from the cities to the reserves and rural communities.[38]

The migration patterns of the registered Indian population reported by Statistics Canada indicated the following:

> Urban areas continued to be the preferred destination of Indian migrants, attracting 56% of all migrants in the 1976-1981 period; in the five years prior to 1971 the figure had been 55%. While urban areas were the recipients of the greatest number of Indian in-migrants, they also contributed an even larger number of Indian out-migrants. In the 1976-81 period, 62% of all Indian migrants originated from urban areas; this is up from 49% in the 1966-71 period. Indian reserves also experienced an increase in their relative share of in-migrants--from 21% in 1966-71 to 28% in 1976-81.
>
> Out-migration from reserves also increased from 13% in 1966-71 to 17% in 1976-81. In terms of net migration (in-migrants minus out-migrants), Indian reserves were net gainers of migrants, while all other areas were net losers over the 1976-81 period. Urban metropolitan areas had a loss of 2% of all Indian migrants in 1976-81, compared to a net gain of 6% of all Indian migrants in the 1966-71 period.[39]

The migration of aboriginal people in and out of their communities may introduce the most remote isolated community to the threat of HIV.

Conclusion

Factors that lead to HIV infection are present in the aboriginal community as in the rest of Canada but high STD rates (indicating unprotected sex with multiple partners), teenage pregnancies and high birth rates indicate that in future, the epidemic may become more prevalent in the heterosexual community as in Pattern II countries.

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[38]National Association of Friendship Centres, Presentation to the Joint National Committee on Aboriginal AIDS Education and Prevention, Ottawa, 1989.

[39]Andrew J. Siggner, The Socio-Demographic Conditions of Registered Indians, Canadian Social Trends, Statistics Canada, Ottawa, 1986.

It is, therefore, important in the development of a National Strategy on Aboriginal AIDS Education and Prevention that emphasis be placed on the role of heterosexual activities in the spread of infection. It is essential that the aboriginal population be made aware that while current available statistics indicate that homosexual/bisexual activity and injection drug use are the main risk factors in transmitting HIV, high STD rates may indicate spread into the heterosexual community. Efforts to reduce the level of STDs should be linked to the National Strategy on AIDS Education and Prevention.

While there is a need to target prevention messages to groups who may engage in high risk behaviours or are particularly vulnerable to HIV infection, due to the close correlation of factors in aboriginal communities and Pattern II countries, educating the entire aboriginal population about the threat of HIV is a priority.

Issue/Question 1.3: What factors lead to the development of HIV spectrum diseases and AIDS?

Findings:

According to the Centers for Disease Control in Atlanta, Georgia, the official definition of AIDS is as follows:

> AIDS is a disabling or life-threatening illness caused by human immunodeficiency virus (HIV) characterized by HIV encephalopathy (brain disease), HIV wasting syndrome, or certain diseases due to immunodeficiency in a person with laboratory evidence for HIV infection or without certain other causes of immunodeficiency.[40]

It is important to understand that while AIDS may be the final result of HIV infection, a variety of other illnesses and diseases may be developed by an individual before being diagnosed as having AIDS.

The U.S. Presidential Commission on the HIV Epidemic pointed out the following:

> Human Immunodeficiency Virus (HIV), the retrovirus which causes AIDS, is actually responsible for human infection with a wide range of consequences. In discussion and planning for appropriate patient care, it is critical to identify the range of patients who will need health care services. A complete patient spectrum starts with persons who are at risk for infection with HIV, ends with those who die of AIDS, and includes everyone in between.[41]

The literature indicates that the immune system is overtaxed by chronic illness and infection. It is logical to assume that if HIV is introduced to an immune system that is already compromised by the presence of another STD, for example, the rate at which HIV spectrum diseases and AIDS are expressed is increased.

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[40]Ron Rowell, Acquired Immune Deficiency Syndrome: The Basics. A Manual for Native American Health and Human Service Workers, National Native American AIDS Prevention Center, Oakland, California, USA, 87.

[41]James D. Watkins, Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, Washington, D.C., June 88.

The Australian-based study on AIDS and Aboriginal people indicated the following:

> ...where an individual has HIV infection and suffers from other chronic disease, the risk of developing AIDS may be higher than for an infected person whose general health is good.[42]

Lack of information about HIV in the aboriginal community and ready access to appropriate health care may prevent timely intervention measures.

Mistrust of the medical system and fear of discrimination may also prevent an aboriginal person from seeking health care even when the symptoms of HIV infection are recognized.

In addition to these factors, many aboriginal cultures perceive disease as "another step in life's journey" and therefore may wish to accept it or consult an elder or traditional healer for guidance. Little is known or documented on the degree to which the development of HIV spectrum diseases and AIDS has been delayed through the use of traditional medicine. However, anecdotal reports indicate that because traditional healing is holistic in its approach, it requires strict adherence to abstinence from alcohol and other foreign substances; appropriate rest and diet and a regiment that is clearly focused on the total being. Although, not scientifically proven, there is some evidence to support that living a "healthy lifestyle" may delay the onset of AIDS once an individual has been tested HIV positive.

Conclusion

The factors that may lead to a more rapid expression of HIV spectrum diseases and AIDS are present in the aboriginal population, including STDs and other chronic illnesses which compromise the immune system. In addition, lack of access to appropriate medical care due to discrimination and mistrust of the system may delay essential intervention and treatment.

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[42]Department of Community Services and Health, Report of the Working Panel on Aboriginals, Torres Strait Islanders and HIV/AIDS, Commonwealth of Australia, 89.

The impact of traditional healing and medicine on HIV spectrum diseases and AIDS is not known at the present time but, there is evidence to suggest that the holistic approach utilized by many traditional healers is beneficial to the individuals who have been tested HIV positive.

Issue/Question 1.4: Are these factors present in the aboriginal population?

Findings:

The research has shown that the factors that contribute to HIV infection and the development of spectrum diseases are present in the aboriginal community namely:

- high risk homosexual/bisexual behaviour,
- injection drug use,
- unsafe heterosexual behaviour and the potential effect on unborn children,
- high STD rates,
- alcohol and drug induced unsafe sexual behaviour, including sexual abuse,
- prostitution as a profession and a means of survival,
- lack of information and access to appropriate services due to discrimination, lack of awareness and distrust.

Conclusion

The majority or sixty-seven percent (67%) of the current Federal Centre for AIDS reported cases of AIDS among aboriginal people have been reported as being acquired through homosexual or bisexual activity compared to eighty-one percent (81%) of reported AIDS cases for Canada. At the present time, based on available numbers, the AIDS epidemic in the aboriginal community appears to mirror that of mainstream Canada. However, largely due to high STD rates, HIV infection may pose a significant threat to heterosexuals in the aboriginal community as in Pattern II countries.

While the majority of the aboriginal population may live in isolated, remote, and rural communities, they are not isolated from HIV infection. The degree to which aboriginal people migrate/travel to and from urban centres has been examined. The degree to which these migrants engage in high risk behaviours while outside of their communities and return to introduce HIV infection to others as in Pattern III countries is not known.

Lack of information, lack of access to health care, mistrust of the medical system, fear of discrimination and cultural considerations may delay intervention of the disease once an aboriginal person is tested HIV positive.

While there is a need to target messages as specific groups who may engage in high risk behaviours in the aboriginal community, educating the entire aboriginal population is a priority.

**Part Two**

Hypothesis Two: There is a need for aboriginal-specific AIDS Education and Prevention programs and activities.

**NOTE:**

The following survey questionnaire was developed to obtain comprehensive information on aboriginal-specific AIDS Education and Prevention programs and activities. Over two thousand (2,000) organizations (aboriginal and non-aboriginal), government offices, band offices, friendship centres, health service providers and Native women's groups across Canada were asked to respond to the questionnaire.

At the time of writing, over 200 responses were received representing a wide sample of service providers. The valuable information and knowledgeable opinions respondents provided is available on request from the Federal Centre for AIDS.

## A. Background Information

Please complete the following to assist in data analysis:

1. Name of Organization/Department/Ministry/Group:

_____
_____

2. Position of person completing this questionnaire:

_____
_____

## B. Aboriginal AIDS Education and Prevention

3. (a) Is your organization involved in any type of AIDS education and prevention program?

( ) Yes ( ) No

(b) If yes, please list activities. If no, please proceed to 3.(e).

_____
_____
_____

(c) Why were these activities initiated? How were these activities initiated? Please describe.

_____
_____
_____
_____
_____

(d) Have these activities demonstrated positive results? How do you know? Please explain.

_____
_____
_____
_____
_____
_____
_____

(e) Who do you think should provide Aboriginal AIDS education and prevention programs and why? Please explain.

4. Is there a need for Aboriginal-specific AIDS education and prevention programs?

( ) Yes ( ) No ( ) Not sure

Please explain:

5. What activities do you think would have the greatest impact on the Aboriginal community?

Please describe:

6. What steps should your organization take to prevent the further spread of HIV in Aboriginal communities?
Please comment:

Issue/Question 2.1: What aboriginal organizations provide AIDS education and prevention programs?

Findings:

A portion of the questionnaire requested descriptive information on AIDS programming - an overview of Aboriginal organizations and groups that provide AIDS education and prevention programming is provided here:

1. **Friendship Centre**

A number of friendship centres including the Micmac Native Friendship Centre in Halifax; the NeChee Friendship Centre in Kenora, Ontario; the Native Friendship Centre of Montreal; and the Pas Friendship Centre in Manitoba; have initiated AIDS workshops and information sessions on AIDS and other STDs.

- These sessions generally included open discussion, video presentations, distribution of printed information and guest speakers from the health services profession.

- Workshops were initiated by the Friendship Centres because they viewed HIV infection as a real threat to the aboriginal people they service.

- All agreed that more education is needed especially on high risk behaviours but, all cited lack of resources and funding as a major obstacle to providing effective Aboriginal AIDS Education and Prevention programming.

- The Prince George Friendship Centre of British Columbia initiated a streetworkers program to distribute condoms, bleach kits, needles and information to aboriginal youth living on the street, in response to the demonstrated need of this high risk group.

2. **First Nations Governments**

First Nations governments, including Parry Island in Ontario, Mohawks of the Bay of Quinte, Ontario; the Glen Vowell Reserve; Grand Rapids of Manitoba; the Williams Lake Band of B.C.; and the Indian Island Band of Rexton, New Brunswick provide

limited education and prevention programming generally through their Community Health Representatives (CHR) or Public Health Nurses.

- Most CHRs and Nurses organized workshops for the general public or specifically designed for other service providers and educators.

- Even though these activities were initiated due to the realization that AIDS is a threat to aboriginal communities, CHRs noted that a major obstacle to either expanding activities or developing new education initiatives, was lack of time and resources.

### 3. Alcohol and Drug Centres

Alcohol and Drug Abuse Centres including the Native People's Alcohol and Drug Centre of Ohsweken, Ontario; and the Alcohol and Drug Centre of Manitoba provide limited counselling services to persons at risk or in response to specific inquiries.

### 4. Gay and Lesbian Groups

Aboriginal gay and lesbian groups such as Gays and Lesbians of the First Nations in Toronto, dispense condoms, organize informal discussion groups on safe sex and offer limited counselling on request.

### 5. Aboriginal Health Services Organizations

The Kativik Regional Board of Health and Social Services, Quebec is translating pamphlets and producing videotapes in Inuktitut on AIDS and STDs. The high rate of STDs among the population they serve motivated the organization but, a lack of resources and time are noted as obstacles to more extensive AIDS education and prevention programming.

Anishnawbe Health of Toronto, in co-operation with the City of Toronto, provides AIDS education and prevention presentations, distribution of condoms and printed information to aboriginal groups on request.

## 6. Aboriginal Representative Groups

Other aboriginal organizations such as the National Association of Friendship Centres and the Native Women's Association of Canada have provided AIDS awareness workshops to their membership at annual meetings, and have encouraged member groups to initiate AIDS prevention training for staff in anticipation of the demand for services.

### Issues Raised by Aboriginal Organizations

- The majority of respondents to the survey questionnaire indicated that a lack of resources, both human and financial, has prevented them from expanding their AIDS education activities.

- All aboriginal activities were initiated as a direct result of awareness of the threat of HIV infection to the population they serve.

Conclusion:

Most AIDS education and prevention activities initiated by aboriginal groups and organizations incorporate existing printed literature presented by health or social service workers in a workshop-style information session. Where relevant videotapes are available or have been specifically produced by the group, they are used to stimulate informal discussions. A few aboriginal organizations target the AIDS education and prevention message to high risk groups, for example, homosexuals, street youth and injection drug users.

An awareness of the threat of AIDS to aboriginal communities is cited as the main reason for initiating a prevention program.

The lack of resources, both human and financial, must be addressed if more comprehensive and effective education and prevention programming are to result from the activities of aboriginal community groups and organizations.

Issue/Question 2.2: What results are these programs/activities demonstrating?

Findings:

The literature and document search failed to provide evidence of any knowledge, attitude and behaviour (KAB) studies on the subject of AIDS and the aboriginal population. While two aboriginal organizations in Ontario (the Association of Iroquois and Allied Indians and, the Union of Ontario Indians in co-operation with the University of Toronto), have initiated proposals for funding consideration by the Federal Centre for AIDS to complete KAB's, no data currently exist in Canada.

Aboriginal organizations and groups who responded to the survey questionnaire and who indicated that they have provided AIDS education and prevention activities/programs, generally felt that an awareness of AIDS-related issues resulted from their efforts.

The following results appear to be occurring within communities where AIDS education has occurred:

- open and frank discussion about safe sex during and after the workshop.
- awareness of the degree of high risk behaviours.
- elimination of myths.
- shared information among youth after workshop.
- increase in request for condoms.
- request for more presentations.
- staff members expressed the need for more training.
- requests for more detailed presentations.

Aboriginal organizations who provided one on one counselling to high risk clients described the following positive results:

- increase in requests for condoms indicating the use of condoms is more acceptable.
- heightened awareness of risks associated with shared needles.
- increase in questions about HIV infection.

A number of aboriginal organizations indicated that because activities are just beginning, the results are difficult to measure in terms of behaviour change.

Conclusion:

Most aboriginal organizations who provide AIDS Education and Prevention programs and activities indicated that they felt they had achieved positive results in terms of heightened awareness and increase in the demand for more information. The demand for condoms and clean needles may indicate positive behavioral change in high risk groups.

No KAB studies on AIDS and the aboriginal population are available to date.

Issue/Question 2.3: Do other organizations or service providers offer AIDS prevention and education programs specifically for aboriginal people?

Have these programs demonstrated positive results?

Findings:

Non-aboriginal AIDS prevention and service organizations across Canada were contacted through the survey questionnaire and asked to describe aboriginal-specific AIDS education and prevention programming they provided.

**Programs and Services Offered**

AIDS organizations, support groups and committees responded as follows:

AIDS Vancouver - have acted as a resource for aboriginal conferences and is interested in training aboriginal resource people.

The results achieved are unknown.

AIDS Saskatoon - attempting to liaise with aboriginal groups and interested in training aboriginal resource people.

Results unknown.

AIDS Vancouver Island - provided workshops to two bands, participated in Tribal Council Health Fair and made a presentation to the Friendship Centre.

Positive comments and increase in requests for presentations.

AIDS Calgary - works with Native alcohol services, liaison with aboriginal agencies and street outreach to aboriginal population.

Requests from aboriginal groups for training.

AIDS Regina - developing an AIDS awareness program for aboriginal people and needle exchange for street population.

Results unknown.

Those AIDS organizations who indicated that they do not provide aboriginal-specific AIDS programming indicated that there was no demand due to lack of an aboriginal population (i.e., Guelph, Ontario). However, they indicated a willingness to provide any assistance on request.

**Community Health Organizations**

Health and Welfare Canada, primarily through Community Health Nurses stationed in reserve, rural and remote aboriginal communities indicated that they provide the following AIDS prevention related activities, with varying degrees of success:

Community workshops - (videotape and discussion) results ranged from great interest demonstrated by requests for more workshops and increase in the demand for condoms, to no one attending.

One on one counselling - increase in number of clients seeking specific information and requests for condoms.

School presentations - (videotape and discussion) increase in interest, positive feedback and open discussion after presentation among peers.

Some community health nurses indicated that because the community is not willing to discuss AIDS, limited information is published in the local newsletter. Information on AIDS is available through brochures displayed at the nursing station.

AIDS education and prevention programs and activities in the Northwest Territories have demonstrated some positive results including requests for HIV testing, demand for information in Inuktitut and increased demand for condoms.

**Issues**

Non-aboriginal respondents to the survey questionnaire frequently indicated that they felt AIDS education and prevention programs and activities would achieve positive results if delivered by aboriginal people due to cultural, language and social differences.

The literature supports this assumption in the case of ethnic minorities in the United States. Because of a basic fear or mistrust of large formal institutions and organizations, the literature indicates that ethnic minorities are less likely than anglos to seek assistance form AIDS organizations and government service providers.

An informal interview with a physician who has many years of experience practising medicine in the North revealed that many aboriginal people have vivid memories of the results of tuberculosis in their communities. "Members of their families would simply be picked up and whisked away to the South, never to be heard from again".

Fear and mistrust of health professionals based on recent history make effective AIDS programming difficult.

Finally, the questionnaire responses from some health care providers revealed a negative attitude toward delivering the AIDS prevention message to aboriginal people. This attitude appears to be based on the fact that workshops on AIDS, for example, have been planned and organized in aboriginal communities but no one attended. The reaction of the health care providers was that aboriginal people "simply don't care", as demonstrated by non-attendance. However, when this problem was raised in an open discussion with AIDS workshop participants at the National Native Women's Association Assembly in October 1989, the women indicated that there are often serious problems with this type of activity due to the judgemental and "preaching" tone of presentations delivered by some health care providers in local communities. It was suggested that aboriginal people should ideally deliver the message but as an interim step, non-aboriginal health care providers should be required to attend training sessions on AIDS prevention and education, with emphasis on cultural differences and sensitive delivery techniques.

## Conclusion

Non-aboriginal AIDS organizations have provided AIDS education and prevention messages to aboriginal people and will continue to respond to these needs. Interest has been expressed by aboriginal organizations to acquire training for their own resource people form these groups. Because non-aboriginal AIDS organizations believe that aboriginal people are in the best position to effectively deliver the message to their own people due to cultural and language considerations, they have indicated interest in training aboriginal resource people.

Some community health nurses have raised awareness of the need to prevent AIDS in aboriginal communities. Most felt that one on one counselling was the most effective means of delivering the message.

The majority of respondents indicated that they believed aboriginal people should be delivering the prevention message but as an interim measure, health care providers should be required to attend training in delivering the AIDS prevention message in a culturally sensitive manner.

Issue/Question 2.4: What types of activities/programs have the greatest impact on the aboriginal community?

Findings:

**Goals of AIDS Education Programs**

The literature indicates that a program or activity designed to prevent the spread of HIV must have as its ultimate goal, sustained behavioral change among all individuals.

Simon Read, Administrator of the Nuu-chah-nulth Health Board in British Columbia commented as follows:

> The fundamental changes in attitudes and activities needed to control the spread of AIDS are the same that will reduce may other health problems among Nuu-chah-nulth people. Obviously, other sexually transmitted diseases spread in much the same way. However the primary causes of the risky lifestyle in many cases go much deeper. They have to do with the breakdown of traditional value systems which taught individual roles and responsibilities within the family and community. They have to do with lack of self-esteem and alienation from society at large. They have to do with individual and family histories which include alcohol, physical and sexual abuse. They have to do in many cases with entrenched dependence, victimization and lack of the skills for self-help and the awareness to reach out for external help.
>
> Prevention of AIDS in Nuu-chah-nulth, and by extension, other native communities ultimately must occur within a comprehensive community health development strategy. This requires both specific education about AIDS and AIDS prevention, and also developing the self-respect to act on that knowledge.[43]

In order for behaviour to change, satisfying alternatives must be introduced. Glen Murray of the Winnipeg-based Village Clinic explained this concept in a presentation to the Joint National Committee:

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[43]Simon Read, A Native Health Organization Perspective on the Prevention of the Spread of AIDS, Nuu-chah-nulth Health Board, Port Alberni, B.C., July 89.

> The change has to be socially satisfying and match the values of the community and provide personal sexual satisfaction. People will not change their behaviour from one that is satisfying to one which does not provide satisfaction.
>
> The change has to have peer or community support. If the community cannot support, accept or be part of what is being said and see it as pleasant, positive and exciting then it won't happen.[44]

For many aboriginal people, their current high risk lifestyle is the only lifestyle they have ever known. They have not been exposed to the alternatives and are therefore, personally unaware of the potential benefits.

The National Aboriginal Communications Society in cooperation with the National Native Alcohol and Drug Abuse Program undertook a media campaign in 1988 to create awareness of addiction issues and realistically present alternative lifestyles to aboriginal people. The objectives of the project were as follows: "to promote a substance abuse free lifestyle, to show such a lifestyle to be the norm, to influence peer group pressure to accept abuse free lifestyles, and to promote participation in community and regional preventative activities."

A review of the project concluded that while attitudinal change was difficult to measure, the campaign generated positive results in that people understood and recalled the message.

Glen Murray of the Village Clinic made the following point:

> If the population in your group does not perceive that the disease is likely to happen to them if they don't change their behaviour, no behaviour change will occur. This is very hard to do with the invisibility of the AIDS virus.

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[44]Glen Murray, Presentation to the Joint National Committee on Aboriginal AIDS Education and Prevention, Winnipeg, Manitoba,
May 28 - 30, 89 (verbatim transcript).

> People have to believe that they can handle the changes required and believe that the changes can be manageable.
>
> People have to fundamentally believe that a change in behaviour is going to significantly reduce or eliminate the risk of getting the disease...
>
> Let communities that are most affected decide how to define the disease. They need to control the agenda, know what it means and what the message should be and how the community can develop its own strategy for survival. They need to identify what kind of behaviourial change they want and what is realistic for their traditional and cultural supports, their beliefs about human life and human sexuality.
>
> Unless one builds a prevention strategy form one's own beliefs and own tradition and heritage, it will not work. Any education program has to pass one litmus test which is...it has to have the capacity to promote sustained behaviourial change. At the present time, this appears to be missing in education programs in Canada.[45]

A major difficulty in providing an effective AIDS prevention message is reaching that portion of the population which is at the highest risk of contracting the disease.

Simon Read comments:

> ...it is not clear that enough information is reaching those at highest risk. The process is complicated because they are the least likely to attend public sessions or to read print material. Young people are often rebellious and reject information as scare tactics, or in the belief that 'it could never happen to me'. For over a year the Nuu-chah-nulth Health Board has been pursuing the means to produce a video targeted specifically to young Native people. We believe that this is the most effective way to reach those who most need to know because virtually everybody

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[45]Glen Murray, Presentation to the Joint National Committee on Aboriginal AIDS Education and Prevention, Winnipeg, Manitoba,
May 28 - 30, 89 (verbatim transcript).

watches television. We can also run such a program through the community cable system in several of our communities.[46]

A group of physicians form the Faculty of Medicine, University of Manitoba, summarized their advice on aboriginal AIDS prevention and education strategies as follows:

> To design effective AIDS prevention programs, objective assessment of the current ratio of HIV positivity and high risk behaviours in Aboriginal communities will be necessary, and outside expertise can and should be called upon to assist in this area. It would be readily available. The programs themselves must be designed and delivered by Aboriginal community members. Evaluation of these programs should be built in from the start, and programs which do not achieve their goals should be replaced with new ideas. Aboriginal people themselves should learn how to perform evaluations. The international experiences should be scanned for new ideas. Aboriginal artists and culture experts should be involved.
>
> With a major preventative effort, it is possible that the spread of AIDS in the Aboriginal community can be prevented. However, this effort will have to result in people actually changing their sexual behaviour. We hope that the programs which are recommended by this committee are ones which will be effective.[47]

As articulated by Glen Murray and others, the ultimate goal of AIDS education and prevention activities ought to be sustained behaviour change. It is reasonable to assume that aboriginal people will attempt to change high risk behaviours when made aware of the life-threatening results. However, it is important to consider the causes of these behaviours when designing a program promoting sustained behaviourial change.

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[46]Simon Read, A Native Health Organization Perspective on the Prevention of the Spread of AIDS, Nuu-chah-nulth Health Board, Port Alberni, B.C., July 89.

[47]Dr. Michael Moffatt, et al AIDS Education and Prevention in Aboriginal Communities, University of Manitoba, Faculty of Medicine, Winnipeg, Manitoba, August 4, 89.

No research could be found examining the sexuality of aboriginal people, all that is documented is that STD rates are much higher than any other group in Canada. The root causes for sexual abuse and alcohol-related deviant behaviour have not been studied but, statistics exist on the prevalence of these behaviours in aboriginal communities.

No documentation could be found on the impact of the social, political and economic disadvantage of aboriginal communities on high risk behaviours.

**Activities With the Greatest Impact**

Respondents to the survey questionnaire described AIDS education and prevention activities that they felt would have the greatest impact on the aboriginal community.

A summary of their comments is provided here:

Demonstrate the real threat of AIDS to the aboriginal community through speakers and video presentations by aboriginal people with AIDS.

Discussions and debates through media that reaches aboriginal population (CBC Radio - North). Encourage the use of aboriginal language where appropriate.

Production of aboriginal-specific cartoons on videotape for use in schools.

Put the disease into perspective with other diseases that have decimated the aboriginal population.

Ongoing community information sessions with changing themes but focusing on the AIDS prevention message.

A travelling AIDS exhibition with HIV testing available, condom distribution and literature.

Comprehensive AIDS prevention training for CHRs and other service providers.

One on one counselling readily available.

Theatre production on AIDS.

Comprehensive AIDS education for aboriginal leadership.

Produce AIDS prevention literature in aboriginal languages.

Involve the church in AIDS prevention through delivery of meaningful messages.

Train aboriginal AIDS prevention workers, especially street workers interacting with aboriginal youth.

Incorporate AIDS education in the elementary school curriculum.

Make condoms and clean needles available in prisons.

Incorporate AIDS education and prevention message in Alcohol and Drug Abuse Centre programs.

Target specific sectors of the aboriginal community for the message, i.e., the business community, the political leadership, educators, service providers, etc. Discuss the effect of AIDS on each sector.

Develop an informal community information and service network.

Repeated and ongoing community information sessions.

Show the effect of AIDS on an aboriginal family.

Involve elders in discussions on sexuality.

Provide peer counselling for teenagers.

Depict alternative lifestyles through video productions.

Promote AIDS education in the workplace.

The majority of respondents to the survey questionnaire indicated that they felt personal presentations to community groups by aboriginal people with AIDS would have the greatest impact on the aboriginal community. Videotapes and films featuring aboriginal people with AIDS were also suggested.

Peer counselling and open discussion were viewed as effective ways of getting the AIDS prevention message across to aboriginal youth.

Training for service providers to ensure effectiveness was recommended.

The use of AIDS-related videotapes featuring aboriginal people was perceived as an effective means of reaching various audiences including families, youth, high risk groups, policy makers and service providers.

Many respondents suggested that where appropriate, AIDS prevention messages should be provided in the aboriginal language of the community.

Conclusion:

AIDS prevention and education activities which will have the greatest impact on the aboriginal community must focus on behavioral change and alternative lifestyles. Sustained behavioral change ought to be the ultimate goal of AIDS education and prevention activities but, there is a need to address the causal effects of high risk behaviours in aboriginal communities.

Aboriginal people are best suited to deliver the AIDS prevention message to their own people but, training and resources are required if the message is to be effective. AIDS prevention messages which demonstrate the threat of HIV infection to aboriginal communities through personal accounts and real life experiences will have the greatest impact.

Issue/Question 2.5: Do aboriginal people currently participate in any non-aboriginal AIDS education and prevention programs?

Findings:

As detailed in Section 2.3 and Chart #1 (Appendices), aboriginal people do participate in non-aboriginal AIDS education and prevention programs but, respondents to the survey questionnaire indicated that due to cultural and language differences, aboriginal people are in the best position to effectively deliver the prevention message to their own people.

Non-aboriginal AIDS organizations have indicated interest in training aboriginal AIDS resource people and aboriginal organizations have initiated discussions with these groups on how best to proceed.

Correspondence revealed that some aboriginal people have sought advice and information on AIDS from non-aboriginal gay and lesbian organizations but, no statistics on the numbers utilizing these services have been documented.

The needle exchange program operated by the Downtown Eastside Youth Activities Society (DEYAS) of Vancouver, British Columbia, has documented that 40% of those serviced through the program are aboriginal people.

Conclusion

Aboriginal people do currently participate in non-aboriginal AIDS education and prevention programs. Although not documented, there is reason to assume that when no other source is available, aboriginal people utilize those that do exist.

Issue/Question 2.6: What steps should First Nations, Aboriginal organizations, Provincial/Territorial and Federal Governments take in educating aboriginal people about AIDS.

Findings:

**The Federal Government**

1. Co-ordinate and deliver resources to support aboriginal AIDS education and prevention programs, projects and activities:

   As an initial step toward educating aboriginal people about AIDS, the Federal Government through the Federal Centre for AIDS (Health and Welfare Canada) initiated the Joint National Committee on Aboriginal AIDS Education and Prevention to design a National Strategy. The strategy will assist the Federal Centre for AIDS in determining program priorities for funding that support AIDS education and prevention activities specifically designed for aboriginal people. The most effective use of limited resources is one of the earliest anticipated outcomes of the National Strategy.

   Where provincial/territorial funds are available it is expected that the Federal Centre for AIDS will assist in co-ordinating the resources necessary to support specific aboriginal programs.

   The research clearly indicates that aboriginal organizations should deliver the AIDS education messages to aboriginal people. The research also clearly indicates that aboriginal health and social service workers are currently overtaxed in terms of workload. The resources available to them are "stretched to the limit" and the time it requires to complete the paperwork to access additional resources is prohibitive. As a result, the Federal Centre for AIDS will be expected to ensure that resources designated for AIDS prevention activities be readily accessible within the financial limitations available to the program.

   The Federal Government has a role to play in facilitating Canada's participation in a World Conference on AIDS and Aboriginal Populations as proposed by the National Association of Friendship Centres at their annual meeting held in July 1989:

**NAFC 18TH ANNUAL GENERAL MEETING**
**JULY 6-9, 1989**
**KELOWNA, BRITISH COLUMBIA**

**RESOLUTION #4**

**SUBJECT:** World Conference on AIDS and Aboriginal Populations

**WHEREAS:** HIV and AIDS poses a serious threat to the health and development of our communities AND WHEREAS; the NAFC is desirous of supporting measures which are intended to educate our communities in ways of preventing the spread of HIV AND WHEREAS; the World Health Organization and the Federal Centre for AIDS have indicated an interest in sponsoring a world conference on AIDS and Aboriginal populations which would involve representatives from the U.S., Australia, New Zealand, Canada and other countries;

**THEREFORE BE IT RESOLVED:** that the NAFC agree to act as host for a World Conference on AIDS and Aboriginal Populations and that the full participation of Friendship Centres be encouraged and assisted.

2. Assist aboriginal communities in the design, delivery and evaluation of AIDS education and prevention programs, projects and activities:

   The Federal Centre for AIDS has assisted aboriginal communities and organizations in establishing linkages with universities and professionals to assist in the design of AIDS programs. Many aboriginal communities and organizations require assistance in designing an AIDS education and prevention program which not only addresses the information needs of the community but monitors the effectiveness of the program in achieving behaviourial change.

   The Department of Indian and Northern Affairs has a role to play in designating the necessary resources to support AIDS prevention curricula in federal schools.

3. Delivery of the AIDS education and prevention message in aboriginal communities:

   The Federal Government, through the Medical Services Branch of Health and Welfare Canada, provides health care services to Indian and Inuit people. The potential impact Medical Services staff could have on

delivering the AIDS prevention message in remote and isolated communities is great. It is important, therefore, that Medical Services staff be sensitive to the unique needs of the communities they service and tailor AIDS prevention activities to suit the people. The involvement of local respected individuals and groups in the delivery of the message is essential.

Health and Welfare Canada co-ordinates and funds the National Native Alcohol and Drug Abuse Program (NNADAP). Respondents to the survey questionnaire indicated that NNADAP Centres should become active in educating aboriginal people about AIDS as a part of their overall responsibilities. AIDS prevention should be incorporated into one on one counselling sessions, printed literature, workshops and school presentations. Special AIDS prevention and special training programs on the subject of AIDS for NNADAP workers has been recommended.

4. Ensure that aboriginal issues are discussed and considered by the Federal/Provincial/Territorial advisory group committee on an on-going basis.

   It is clear that the needs of the aboriginal population in receiving the AIDS prevention message are different from mainstream Canadian society. It is the responsibility of the Federal Government to bring these matters to the attention of the advisory group on an on-going basis to ensure that Canada's National Strategy is indeed, effectively addressing the needs of <u>all</u> people.

5. Participation in on-going discussions with aboriginal groups.

   A representative of a national aboriginal organization, in an informal interview, recommended that the Joint National Committee on Aboriginal AIDS Education and Prevention be given a new mandate and remain intact for a minimum of one year after the National Strategy is implemented to monitor progress and effectiveness.

   The Native Women's Association of Canada as a part of Resolution #28, October 1989 recommended the following:

AND FURTHER BE IT RESOLVED THAT, an aboriginal committee be set up to monitor effectiveness of the strategy and to recommend changes and additions to the strategy;

Aboriginal organizations have expressed concern over the federal government's policy to transfer responsibility for delivering Medical Services to First Nations.

Because the financial implications of caring for aboriginal people with AIDS has not been assessed and provisions to cover the costs of mental health care (as in AIDS dementia) are currently not covered, aboriginal organizations are reluctant to accept responsibility for Medical Services utilizing current funding formulae.

The Native Women's Association of Canada in Resolution #28 recommended the following:

AND FINALLY BE IT RESOLVED THAT, before Medical Services are transferred to First Nations, resources be allocated to cover the additional costs projected for Health Care associated with AIDS and mental health.

**Provincial and Territorial Governments**

1. Co-ordinate and deliver resources to support aboriginal AIDS education and prevention programs, projects and activities.

   The Governments of the NWT, Yukon, Ontario, Manitoba, and British Columbia have been involved in aboriginal AIDS education and prevention programming either through providing direct financial support to aboriginal organizations delivering programs (i.e., Ontario Ministry of Health funding for the Union of Ontario Indians AIDS Prevention Program) or through the development and delivery of aboriginal-specific AIDS prevention messages as in B.C. and the NWT. Because health issues impacting the Indian and Inuit population are the responsibility of the Federal Government, some respondents expressed concern that the provinces have been slow to address the needs of aboriginal communities.

However, aboriginal communities and groups outside the responsibility of the Federal Government, including some urban-based aboriginal organizations and social service agencies have accessed provincial funding to support street worker programs, counsellors and referral networks.

An informant noted that the continued support of provincial and territorial governments is required and indeed, where no special provision or policy is in place to articulate the provincial/territorial government's role in aboriginal AIDS education and prevention programming, urgent consideration ought to be encouraged.

2. Assist aboriginal communities in the design, delivery and evaluation of AIDS education and prevention programs, projects and activities.

   Provincial/Territorial governments can be of assistance to aboriginal organizations, groups and communities in designing effective AIDS prevention programs. The medical and scientific expertise they can access would be beneficial to aboriginal community groups who are designing programs to meet specific needs.

3. Ensure that aboriginal issues are discussed and considered by the Federal/Provincial/Territorial advisory group on an on-going basis: the needs of aboriginal communities with respect to AIDS education and prevention within the various provinces and territories ought to be raised at the national level on a continuous basis by provincial/ territorial representatives or through some other mechanism.

4. Participate in on-going discussions with aboriginal groups: mechanisms to accommodate on-going discussions with aboriginal groups on the effectiveness of AIDS education and prevention programs and unmet needs ought to be established in all provinces and territories.

**Aboriginal Organizations**

1. Assist aboriginal communities in accessing appropriate resources to design, deliver and evaluate AIDS education and prevention programs: national aboriginal organizations who participate on the Joint National Committee on Aboriginal AIDS Education and Prevention have taken a first step in assisting the communities they represent.

   The Native Women's Association of Canada organized a two-day workshop on AIDS for their annual meeting in October 1989 where the following resolution resulted:

**RESOLUTION #28** **JILLEN JULIAN, NOVA SCOTIA, EAST REGION/GRACE ZOLDY, MANITOBA, SOUTH REGION**

WHEREAS, AIDS is a major concern to us; and

WHEREAS, not enough attention is being given to the issue;

BE IT RESOLVED THAT, the Native Women's Association of Canada lobby the Department of Health and Welfare Canada to make AIDS a priority and hire natives to deliver the message;

FURTHER BE IT RESOLVED THAT, the Native Women's Association of Canada lobby First Nations who are self-governing to make AIDS a priority to deliver the message; and

AND FURTHER BE IT RESOLVED THAT, AIDS training packages for trainers and/or service providers be designed, developed and delivered in our communities and resourced by the Department of Health and Welfare Canada; and

FURTHER BE IT RESOLVED THAT, an International Conference of Indigenous people and AIDS be pursued; and

FURTHER BE IT RESOLVED THAT, there be a wide distribution and access to:
(1) National Strategy;
(2) Background research documents.

AND FURTHER BE IT RESOLVED THAT, an aboriginal committee be set up to monitor effectiveness of the strategy and to recommend changes and additions to the strategy; and

AND FINALLY BE IT RESOLVED THAT, before Medical Services are transferred to First Nations, resources be allocated to cover the additional costs projected for Health Care associated with AIDS and mental health.

**AGREED BY CONSENSUS**

The National Association of Friendship Centres, along with three other recent initiatives has appointed a national representative to continue to move the need for aboriginal AIDS education and prevention measures for ard.

Aboriginal organizations have a role to play in advising the Federal\Provincial\Territorial Advisory Committee on AIDS either as participants or through some other effective mechanisms to ensure that adequate resources are allocated to aboriginal initiatives.

2. Delivery of AIDS Prevention and Education Programs

Respondents noted that aboriginal organizations have responsibility for ensuring that staff are trained and well-informed so that the population they serve receive accurate and relevant information.

As detailed in Chart #2, the overwhelming majority of respondents to the survey questionnaire said they felt aboriginal people should deliver aboriginal-specific AIDS education and prevention programs. The need for quality programming and quality training for staff will have to be addressed by aboriginal

organizations. The development of staff support networks and resource sharing may necessitate co-ordination on the part of aboriginal organizations.

3. Monitoring the effectiveness of AIDS Education and Prevention Programs

   Respondents to the survey questionnaire indicated that aboriginal organizations must take a leadership role in recognizing HIV infection as a serious threat to the aboriginal population and demonstrate this recognition by making AIDS education and prevention a priority. One respondent suggested that a brief discussion on the disease including new initiatives to prevent the spread of HIV and an update on the reported number of AIDS cases among the aboriginal population should be included on the agenda of each meeting no matter what the subject.

   The NAFC has implemented a monitoring process much as described above. Board representatives report on AIDS prevention activities at each meeting and identify additional needs.

   In response to the "Call for Papers", physicians from the Faculty of Medicine, University of Manitoba made the following point:

   > So many counselling programs are ineffective that they waste money. Aboriginal leaders should ensure that each program introduced is evaluated, and that ineffective programs are discarded and money redirected into new ideas. They need to ensure that there are aboriginal resources to do this and when there are not, university and other resources should be called upon. These resources should be asked to perform the initial evaluations but also to train Aboriginal people to perform such evaluations.[48]

4. Demonstrate an exemplary role in the prevention of AIDS in aboriginal communities.

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[48]Dr. Michael Moffatt, et al AIDS Education and Prevention in Aboriginal Communities, University of Manitoba, Faculty of Medicine, Winnipeg, Manitoba, August 4, 89.

Aboriginal organizations are distributing condoms and establishing needle exchange programs for the community they serve.

Some organizations have expressed interest in initiating needed KAB studies and are proposing sponsorship of national impact campaigns.

Finally, aboriginal organizations are realizing that AIDS presents a serious threat to aboriginal communities and are demonstrating concern and understanding through open discussion and promotion of prevention activities.

**First Nations**

Interviews with key informants and others indicated that, it is the responsibility of First Nations to initiate aboriginal AIDS education and prevention programs by stimulating community interest and concern and by defining what messages are acceptable and will have the greatest impact on their communities.

Policy makers, decision makers and health service providers have an essential role to play in initiating, designing and delivering AIDS education and prevention programs to the community.

With the necessary resources and expertise, First Nations communities will be assisted in monitoring the results of their efforts.

Conclusion:

Respondents indicated that, demonstrated recognition of the threat HIV infection poses to the aboriginal population is the first and most critical step in designing and delivering AIDS education and prevention programs. Further steps will be dependent on the commitment of all levels of government including aboriginal governments.

The research both primary and secondary, indicated very clear roles and responsibilities for the various levels of government.

The Federal Government has an important role in; co-ordinating and providing the necessary resources to support aboriginal AIDS education and prevention programs; assisting aboriginal communities in the design, delivery and evaluation of programs; delivering

culturally-specific prevention messages in aboriginal communities; ensuring that issues of particular concern to the aboriginal population are considered by the Federal/Provincial/Territorial AIDS Advisory Committee; and, participating in on-going discussions with aboriginal groups as a means of identifying additional needs and concerns.

Provincial and Territorial Governments have a similar role to fulfil in addressing the AIDS education and prevention needs of aboriginal people. Assistance in identifying and linking appropriate expertise to aboriginal communities who are designing and planning to deliver AIDS prevention and education programs is necessary. Provinces and Territories have a responsibility for raising the specific concerns of aboriginal groups and communities within their boundaries at the Federal/Provincial/Territorial AIDS Advisory Committee level and where none exist, mechanisms for on-going communication with aboriginal AIDS prevention and education groups ought to be established.

Aboriginal organizations have an essential role to play in assisting aboriginal communities in accessing appropriate resources and expertise to support AIDS education and prevention measures. In addition to assisting aboriginal communities through training

initiatives for resource people and establishing support networks, aboriginal organizations have responsibility for monitoring the effectiveness of the National Strategy on Aboriginal AIDS Education and Prevention through working with the Federal Government to ensure that the Strategy is carried out and is indeed meeting the needs of the aboriginal population.

First Nations and aboriginal organizations alike have an exemplary role to play in realizing the real threat of AIDS to the aboriginal community and in initiating and monitoring effective prevention measures.

Issue/Question 2.7: Is AIDS education and prevention a priority in aboriginal communities?

Findings:

While some aboriginal groups and organizations, particularly those with social and health service responsibilities, have initiated AIDS Education and Prevention programs, the evidence suggests that AIDS is not viewed as a priority by many aboriginal communities.

One of the reasons why the prevention of AIDS may not be viewed as a priority, is a general lack of knowledge about the disease and resulting misconceptions. The following point was raised by Simon Read, Administrator of the Nuu-chah-nulth Health Board in British Columbia:

> Three years ago the perspective on AIDS in Nuu-chah-nulth communities was that it was not our problem. Our health priorities reflected two myths which were widespread at the time. One was that AIDS was primarily a disease of male homosexuals and intravenous drug users in the ghettos of large U.S. cities. The other was that there was little if any risk behaviour in the local area.
>
> In late 1987, about the same time that the first case was officially reported on Vancouver Island, rumours began circulating in Nuu-chah-nulth communities. The first reaction was panic, a fear of widespread contagion. The Nuu-chah-nulth Health Board at that time added AIDS to its preventive health program, with the goal of getting the facts about AIDS into the communities.[49]

When the threat of AIDS appears imminent, aboriginal communities may react out of fear. Because of a general lack of awareness or misconceptions, the reaction is often negative and unfocused.

Respondents to the survey questionnaire indicated that the perception of AIDS as a "homosexual or drug addict" disease centred in large urban centres is widespread. Thus, the attitude of, "it won't happen here". Some health care respondents indicated that while they had

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[49]Simon Read, A Native Health Organization Perspective on the Prevention of the Spread of AIDS, Nuu-chah-nulth Health Board, Port Alberni, B.C., July 89.

organized community information sessions on AIDS, attendance was minimal. However, it is difficult to assess whether low attendance indicates a lack of interest in AIDS, a lack of interest in health issues generally, or problems associated with the presentation. Many respondents noted that when the message was presented in an open and frank manner by an individual who was familiar with the community, significantly more interest was demonstrated by the public.

In addition to misconceptions resulting from lack of knowledge about the disease, many aboriginal communities do not view AIDS as a priority issue because of many other day-to-day health and social problems. Aboriginal communities in Australia share this perspective:

> Community priorities
>
> As a rule, Aboriginal communities have many health and social problems and HIV infection is the least visible and the least pressing. Therefore, while AIDS is frightening, it is not on the agenda for many communities nor the administrators of organisations...
>
> The widespread ill-health and socio-economic disadvantage in Aboriginal and Islander communities have implications for any discussion intending to address the education, prevention and treatment needs of Aboriginal people with regard to HIV infection/AIDS. It helps to explain why HIV infection is not high on the agenda for community leaders - there are many other more visible and pressing priorities.[50]

While aboriginal communities may view AIDS as a "future" threat, they lack the human and financial resources to deal with present day issues and therefore, prevention programming is often not practical or affordable.

Black and Latino communities in the U.S. expressed similar concerns:

> Another frequently cited obstacle [to AIDS prevention] is the perception that a group is already overwhelmed by its existing mission. Most community-based organizations are under-funded and

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[50]Department of Community Services and Health, Report of the Working Panel on Aboriginals, Torres Strait Islanders and HIV/AIDS, Commonwealth of Australia, 89.

> under-staffed. To begin to address an issue as complicated and controversial as AIDS may seem like more than a group can handle. Moreover, the constituencies they serve are also overwhelmed by other problems. 'This population is so poorly served,' said the director of a mental health agency. 'Outreach into the community where there are no human services at all desperately needs to be done. And you have to do it before you expect people to care about AIDS. AIDS is one more thing - part of a whole lot of other things which can go, which are going wrong'.[51]

Respondents to the survey questionnaire frequently cited lack of trained staff, lack of relevant printed information and lack of time due to workload as obstacles to making AIDS prevention programming a priority.

On the other hand, some aboriginal organizations are becoming actively involved in developing AIDS prevention programs and policies. Anishnawbe Health of Toronto, in cooperation with the City of Toronto has hired a Native Community Health Worker to provide AIDS prevention messages and distribute condoms and printed information to inner-city aboriginal groups. This program has been so successful that many requests for presentations have come in to the Toronto-based office from surrounding aboriginal communities, where no such service is available. Many Alcohol and Drug Abuse Centres as well as aboriginal gay and lesbian groups have made AIDS prevention and education a priority. The Association of Iroquois and Allied Indians in Ontario, have been involved in AIDS prevention for over a one and one-half years including participation on an AIDS Committee for Ontario which developed posters and brochures, developed a KAB (knowledge, attitude and behaviour) study format proposal for funding consideration by the Federal Centre for AIDS and a proposal for a travelling exhibition.

At the request of the National body, the Ontario Federation of Indian Friendship Centres, plans to integrate AIDS public information into future Native Community Development Workers training packages.

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[51]Freudenberg et al, How Black and Latino Community Organizations Respond to the AIDS Epidemic: A Case Study in One New York City Neighborhood, AIDS Education and Prevention, The Guilford Press, New York, USA, 1989.

The First Nations represented by Manitoba Keewatinowi Okimakank Inc. considered the following resolution at their June 1989 Annual Assembly:

**WHEREAS** The AIDS epidemic is the most serious public health issue that faces Native people; and

**WHEREAS** The Chiefs of MKO realize the seriousness of the AIDS epidemic; and

**WHEREAS** MKO represents the views and opinions of member Bands, including women and children; and

**WHEREAS** The AIDS epidemic is a high priority with the Chiefs of MKO;

**THEREFORE BE IT RESOLVED**

That the Chiefs of MKO support the establishment of an AIDS resource centre in the North that would provide AIDS related information.[52]

The Prince George Friendship Centre in British Columbia has made AIDS prevention a priority through their street workers program where they distribute condoms, needles and bleach kits to aboriginal youth living on the streets.

The National Association of Friendship Centres passed a resolution in July, 1989 proposing an International Indigenous Peoples Conference on AIDS. The proposed conference will focus worldwide attention on the threat of HIV infection to indigenous populations in Canada, the US, Australia, and New Zealand.

Finally, all National aboriginal organizations nominated representatives to the Joint National Committee on AIDS Prevention and Education to facilitate the development of the National Strategy in cooperation with the Federal Centre for AIDS.

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[52]David Merasty, MKO Response to Call for Papers, Nelson House Indian Reserve, Manitoba, August 2, 1989.

Conclusion:

Although generally, aboriginal people at the community level do not view AIDS education and prevention as a priority due to lack of knowledge, more visible and pressing social and health issues and lack of human and financial resources, aboriginal organizations who view the disease as a threat to the population they serve (Friendship Centres, Alcohol and Drug Abuse Centres, gay and lesbian organizations, women's groups, and some politically mandated groups) are giving AIDS prevention and education programming more and more attention.

## Overall Conclusion

The research indicated that there is a need for aboriginal-specific AIDS education and prevention activities and that the message would be most effective if delivered by aboriginal resource people.

Aboriginal organizations including Friendship Centres, Social and Health service providers, First Nations and others have initiated AIDS prevention activities which have succeeded in raising the level of awareness about the threat of HIV to the aboriginal population.

The services of mainstream AIDS organizations may be best utilized by aboriginal communities to establish linkages with them for the purpose of acquiring training for their resource people.

Non-aboriginal health care workers who are responsible for delivering the AIDS prevention message would benefit from training which emphasizes cultural sensitivity.

Federal, Provincial and Territorial governments have essential roles in aboriginal AIDS education and prevention including; resource allocation and co-ordination; service delivery; assisting in program design, delivery and evaluation; and, ensuring that the unique concerns and needs of aboriginal communities are identified and actioned by the appropriate level of government. Aboriginal organizations have responsibility for interacting with all levels of government on behalf of the aboriginal population; establishing training programs and support networks for service providers; and monitoring the effectiveness of the National Strategy. First Nations have responsibility for initiating and monitoring effective AIDS prevention measures in their communities.

AIDS is viewed as a priority by aboriginal people and their representative organizations when they are aware of the issues and potential threat of AIDS to their communities.

While other more visible social and health issues have been the focus of many aboriginal communities, increased knowledge will result in a greater demand for human and financial resources to support AIDS education and prevention activities.

**PART THREE**

OTHER RELATED ISSUES - HIV Testing

- Research Priorities

HIV TESTING

## Human Immunodeficiency Virus (HIV) Testing

Over the course of the research, and particularly during informal discussions and meetings with various aboriginal groups, the issue of testing for the HIV virus has emerged repeatedly. Opinions on who ought to be tested have ranged from, "everyone ought to be tested as in the tuberculosis epidemic" to, "the privacy of all people should be respected and therefore only voluntary testing should be required".

Many people believe that certain occupational groups should be tested as a condition of employment, for example, day care workers. However, when a thorough understanding is established of how the virus is transmitted these opinions change.

In answer to the question, "Why should we test for HIV?", the literature indicated the following:

A Canadian perspective:

1. To prevent most transfusions, transplantation, or artificial insemination from infected donors;
2. To help in the diagnosis of suspected HIV diseases, or confirming their association with HIV infections;
3. To help individuals to protect themselves and others from HIV infection, including promoting safe behaviour;
4. To help to direct public health programmes, through surveillance;
5. To improve, through its use in research, understanding of HIV infection, the diseases it can produce, and methods to detect and treat HIV infection and disease."[53]

The U.S. Presidential Commission indicated the following:

> The HIV antibody test is used for several reasons. First, it can determine an early clinical diagnosis of HIV infection which should immediately establish a strong link between an infected individual and a primary health care provider. Second, it is used to screen donated

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[53]M.A. Somerville and N. Gilmore, Human Immunodeficiency Virus Antibody Testing in Canada, McGill, Montreal, January 1988.

blood, organs, breast milk, and semen to protect the eventual recipient. Third, test results are used to establish incidence and prevalence data, critical to monitoring the epidemic. Fourth, testresults can be used to initiate a process whereby partners are warned of their exposure to the virus. Finally, testing and counselling are a vital component in encouraging positive behaviour change in an individual.[54]

In the United States, the HIV test is required of all military personnel as a condition of their entering the service. The data collected from those tests has revealed that HIV is prevalent in the Native American population and in some areas of the country, HIV is more prevalent than others:

U.S. Military Seroprevalence Rate per 1,000 By Ethnicity

10/85 to 12/88

| | |
|---|---|
| White | 0.6 |
| Black | 3.7 |
| Hispanic | 2.0 |
| American Indian/Alaska Native | 1.1 |
| Asian | 0.5 |

California U.S. Military Seroprevalence Rate per 1,000 By Ethnicity 10/85 to 12/88[55]

| | |
|---|---|
| White | 0.1 |
| Black | 5.6 |
| Hispanic | 0.9 |
| American Indian/Alaska Native | 4.4 |
| Asian | 0.4 |

[54]Watkins, Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, Washington, D.C., USA, June 24, 1988.

[55]United States Department of Defense Seroprevalence Data, Centers for Disease Control, Atlanta, Georgia, 1989.

In data relating to all individuals entering the U.S. military over the three-year period, Native Americans were the third largest group testing HIV positive. In data relating to individuals from California (the largest Native American population in the U.S.) entering the military, Native Americans were the second largest group testing HIV positive.

The figures have been used by the Native American AIDS Prevention organization not only to argue for increased resources to support AIDS education and prevention activities but, to convince Native Americans themselves that their population is indeed at risk.

In answer to the question, "Who should we test for HIV?", the literature indicated the following:

From the McGill University position, 1988:

Voluntary HIV antibody testing **may be advisable** for:

1. Persons who, since 1978, have received unscreened blood transfusions;
2. Health care personnel who may have been accidentally occupationally exposed to HIV;
3. Persons in non-correctional or correctional facilities.

Voluntary HIV antibody testing is **recommended** for:

1. Persons who, since 1978, have received tissue or organ transplants from unscreened donors;
2. Women who, since 1978, have been artificially inseminated with semen (sperm) from an unscreened donor;
3. Residents of areas where HIV infection is endemic;
4. Men engaging in risk-producing homosexual activity;
5. Persons working in the sex industry;
6. Persons being evaluated for sexually transmitted diseases.

Voluntary HIV antibody testing is **strongly recommended** for:

1. Persons who, since 1978, have received unscreened blood products;

2. Persons sharing injection equipment during drug use;
3. Health care personnel who have had documented accidental occupational exposure to HIV;
4. Persons seeking or receiving health care who are the source of accidental occupational exposure of health care workers."[56]

The Centers for Disease Control in the U.S. indicated the following:

> **Counselling and testing programs**. Informing and educating persons about whether they themselves are infected with HIV is an important way to prevent HIV transmission. CDC is encouraging widespread counselling and testing for HIV antibody among people whose behaviour has increased their risk for HIV infection. In 1985, CDC funded 55 State and local health departments to establish sites for HIV testing and counselling. By June 1987 approximately 1,100 public counselling and testing sites were operating in the United States.
>
> Counselling to assess and reduce risk and testing of serum from all patients is now encouraged in sexually transmitted diseases (STD) clinics, drug treatment facilities, and tuberculosis treatment clinics."[57]

Canadian Public Health Law indicates the following:

> Several jurisdictions have laws or regulations obliging persons who believe themselves to be infected to seek medical treatment. In some the obligation applies for communicable diseases in general. These include Alberta, Prince Edward Island and the Northwest Territories.

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[56]M.A. Somerville and N. Gilmore, Human Immunodeficiency Virus Antibody Testing in Canada, McGill, Montreal, January 1988.

[57]James Mason et al, Current CDC Efforts to Prevent and Control Human Immunodeficiency Virus Infection and AIDS in the United States through Information and Education, CDC, June 1988, Atlanta, Georgia, USA.

Other provinces create this duty in the particular case of sexually transmitted diseases. Included in this group are British Columbia, New Brunswick, Newfoundland, and Saskatchewan. Quebec applies this duty to sexually transmitted diseases and tuberculosis.

Interestingly, no such general obligation is created under the Ontario Health Protection and Promotion Act, 1983.

The essence of these enactments is contained in s.31(1) of the Alberta Public Health Act:

> Every person who knows or has reason to believe that he is or may be infected with a communicable disease...shall immediately consult a physician to determine whether he is infected or not, and if he is found to be infected, shall submit to the treatment directed by the physician until the physician is satisfied that he is not infectious.
>
> In other words, not only a person who knows he actually has the disease must consult a doctor. A person who believes that he may be infected must also do so. The words "has reason to believe" mean that an objective standard of belief applies. A person cannot wilfully close his eyes to signs and symptoms and thus escape liability if a reasonable person would suspect a possible infection. In the context of AIDS such an enactment might mean that a person in a high risk group with some symptoms of the disease would have an obligation to seek medical counsel."[58]

Ron Rowell, Director of the National Native American AIDS Prevention Centre in the U.S. offered the following advice to women who plan to become pregnant:

> For women at risk (ie., women with multiple sexual partners, women who use IV drugs, and the sexual partners of homosexual/bisexual men, IV drug users, or other infected persons):

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[58]Robert Friedman, The Application of Canadian Public Health Law to AIDS, Health Law in Canada, 1988.

- If you plan to become pregnant, consider taking the HIV antibody Test to see if you've been exposed.

- If you test positive, do not become pregnant. Not only can you pass the virus to your baby, the chance of your developing full-blown AIDS may be made greater by becoming pregnant."[59]

The literature pointed out that before HIV testing is initiated, the privacy and well-being of the individual being tested must be guaranteed. In response to the question, "What is required before testing is initiated?", the following resulted:

The World Health Organization:

> **Testing:** Testing for HIV antibodies is usually performed in hospitals, health centres or at sexually transmitted disease treatment clinics. Testing should always be confidential and the results provided in a private manner with an opportunity for the person tested to discuss the result with a knowledgeable counsellor."[60]

From the report of the Working Panel on Aboriginals and Torres Strait Islanders, Australia:

> **Confidentiality**
>
> There is enormous concern about maintaining the individual's confidentiality regarding counselling, HIV testing and HIV status. This concern is acute in the prison environment. Maintaining confidentiality is a continuing challenge for all organisations involved in programs and services relating to HIV infection. Community organisations had a concern about breaches of confidentiality from people outside an Aboriginal or Islander community and also breaches from...

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[59]Ron Rowell, Acquired Immune Deficiency Syndrome: The Basics, National Native American AIDS Prevention Centre, Oakland, California, USA, 1988.

[60]World Health Organization, Global

> The dilemma of individual confidentiality versus the needs of the community was also raised."[61]

The U.S. literature revealed the following:

> Confidentiality has always been a strictly observed principle in medicine and public health. Sensitive topics have always by necessity been a routine part of interviews and records in these fields. However, for AIDS, because of the social disdain toward the two highest risk groups, and the illegal status of IV drug use, and the numerous antisodomy laws, even stricter assurances are required. In some states, like California, legislation has been passed to strengthen these confidentiality assurances. In some situations such laws have caused problems and have prevented essential communications between physicians and practitioners of public health. But this is an evolving field and, as such, there is constant change and adjustment. The public's confidence in the public and private sectors' protection of their privacy depends on repeated examples and public stands taken by all involved in AIDS treatment and prevention. With positive examples many of the difficulties centred around serologic testing and contact tracing/notification will abate."[62]

McGill University position of HIV testing noted the following:

> HIV antibody testing should only be done when voluntary, that is with informed consent, and when counselling and education before and following testing are available and offered, and when confidentiality of results or anonymity of testing can be guaranteed."[63]

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[61]Department of Community Services and Health, Report of the Working Panel on Aboriginals, Torres Strait Islanders and HIV/AIDS, Commonwealth of Australia, 1989.

[62]Francis and Chin, The Prevention of Acquired Immunodeficiency Syndrome in the United States, Journal of the American Medical Association, March 1987.

[63]M.A. Somerville and N. Gilmore, Human Immunodeficiency Virus Antibody Testing in Canada, McGill, Montreal, January 1988.

In the Guide to Planning (for an AIDS Program), the World Health Organization advised on Counselling:

Pre and Post Test Counselling:

> **Pre-and Post Test Counselling:** Discussing the facts and issues about HIV infection with a counsellor can help in making a decision about whether or not to have an HIV antibody test. Counselling provides an opportunity to talk about the reasons for testing. Counselling after testing is equally important for people with negative or positive test results. For those not infected it is important to ensure that their anxiety has been relieved and that they understand how to remain safe from infection.
>
> **Counselling for People with HIV infection:** People with HIV infection can be assisted through encouraging or facilitating their meeting together to share experiences and concerns. Individual anxieties may be further dealt with in confidence with a counsellor. This counselling often needs to be provided as long-term support and may need to be increased during periods of illness."[64]

Ron Rowell, Director of the National Native American AIDS Prevention Center described pre-test counselling:

> Therefore, anyone considering taking the test should receive pre-test counselling to include:
>
> 1. The medical meaning of the test
> 2. Transmission of HIV, including the role of reinfection as a co-factor in progression to AIDS
> 3. Legal issues, including possible consequences for insurance coverage
> 4. Identifying behaviours which affect overall health and the function of the immune system

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[64]World Health Organization, Global Programmes on AIDS, AIDS Health Promotion: Guide to Planning, Geneva, Switzerland, 1988.

5. Identifying community support services and possible experimental treatments available for seropositive persons."[65]

The following concerns were expressed by the indigenous people of Australia:

> There was concern expressed that Aboriginal people would be coerced into being tested for HIV infection without individual and informed consent. Communities were of the view that, where community screening had taken place, those who were most at risk were least likely to present for testing. However, when testing was voluntary and encouraged in a positive way, those at risk were likely to attend.[66]

In terms of Compulsory Testing, the position of the McGill University document is as follows:

> This document recommends that, as a general principle, compulsory HIV antibody testing is unwarranted in Canada. However, there are likely to be rare exceptions to this principle. In these situations, for example the possibility of compulsory testing of persons convicted of violent sexual offence, these exceptions must be examined on a case-by-case basis.[67]

Surveillance, Research and Anonymous Testing

Although there is scientific justification for initiating testing programs which are population based, some aboriginal people are not entirely supportive of this type of research initiative: the reasons for their reluctance are:

(1) Numbers of HIV positive aboriginal people will further stigmatize the aboriginal population, and

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[65]Ron Rowell, Acquired Immune Deficiency Syndrome: The Basics, National Native American AIDS Prevention Center, Oakland, California, USA, 1988.

[66]Department of Community Services and Health, Report of the Working Panel on Aboriginals, Torres Strait Islanders and HIV/AIDS, Commonwealth of Australia, 1989.

[67]M.A. Somerville and N. Gilmore, Human Immunodeficiency Virus Antibody Testing in Canada, McGill, Montreal, January 1988.

(2) Existing cases of AIDS among the aboriginal population are enough justification for AIDS education and prevention measures.

The position of HIV put forward by McGill University outlined the following:

Surveillance, Research and Anonymous Testing

The collection of HIV antibody testing data for purposes of surveillance or research is a legitimate and necessary activity. There is urgent need for these data. This collection may be done: prospectively or retrospectively; with or without personal identification of the person being tested, or of specimens and data (i.e., nominal, non-nominal, or anonymous testing); or with results that are linked or unlinked to the person as source of the specimen. Where personal identifiers are used, or where results can be linked to an individual, then all persons being tested:

i. Must be fully informed of the potential benefits, benefits, potential harms and harms of such testing;

ii Must consent to being tested;

iii Must have access to their own results, and to care, counselling and interventicns that their results may require;

iv Must be given a guarantee of confidentiality of results.

National seroprevalence data are urgently needed in Canada. The conditions for collection of such data have been reviewed by the National Advisory Committee on AIDS, and they have recommended [NAC -AIDS (19/10/87) 3.2] that:

'Health and Welfare Canada should be encouraged to obtain or support the collection of data on the seroprevalence of HIV infection in Canada, adhering to the following conditions in the development and design of HIV antibody seroprevalence studies:

1. Ethnically justified studies should only be conducted in a blinded (unlinked) anonymous fashion;
2. Ethnically justified studies should only be done on specimens which have been obtained for other routine tests;
3. Only demographic information already attached to such specimens should be collected;
4. Voluntary HIV antibody testing under the conditions of informed consent, pre-/post-test counselling, and confidentiality must be accessible to persons who are being seen in the proposed study setting'.[68]

Finally, when the literature was reviewed to discover the potential drawbacks and benefits to HIV testing, the McGill University paper noted the following:

Drawbacks

1. Discovery of seropositivity can be a grave psychological stress for the person being tested;
2. Persons who are HIV antibody seropositive may be at risk of losing their friends, employment, insurance, housing and educational or travel opportunities;
3. Some persons being tested may be labelled as being seropositive when not infected (false positives), and some persons may be labelled as seronegative when infected with HIV (false negatives);
4. The costs of HIV antibody testing, itself, and of unavoidable harms of testing, including the costs of their consequences.

Benefits

1. Establishing or clarifying a diagnosis of HIV infection or disease, enabling such persons to receive appropriate health care;
2. Minimizing the danger of therapy with potentially immunosuppressive drugs for persons who are HIV infected;
3. Reassuring seronegative persons that they are unlikely to be infected;

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[68]M.A. Somerville and N. Gilmore, Human Immunodeficiency Virus Antibody Testing in Canada, McGill, Montreal, January 1988.

4. Motivating or persuading uninfected persons to avoid exposure to HIV, or HIV infected persons to avoid re-exposure to HIV and to other potentially harmful agents;
5. Enabling persons to become pregnant, or to engage safely in unprotected sexual activity, without endangering their partners who are also not infected, when testing shows these persons are not infected, even though they have engaged in activities that can transmit HIV;
6. Enabling persons to work or engage in specific activities that could be a health risk for them if they are immunodeficient, or could potentially transmit HIV to others;
7. Enabling HIV seronegative persons to travel, work, be educated, or reside in countries where this may be prohibited for HIV infected persons.[69]

## Conclusion

The information provided here is not meant to be conclusive but rather, is provided to stimulate discussion and thought in the aboriginal community around the issue of HIV testing. While there is an obvious need for HIV testing in primary health care as a diagnostic tool, the need for seroprevalence data to monitor HIV in the aboriginal community is questionable.

To delay the delivery of AIDS education and prevention messages in aboriginal communities in anticipation of the results of seroprevalence data is not advisable nor justifiable since, there is evidence that HIV infection does exist and this fact alone, indicates the need for immediate action.

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[69]M.A. Somerville and N. Gilmore, Human Immunodeficiency Virus Antibody Testing in Canada, McGill, Montreal, January 1988.

# RESEARCH PRIORITIES

## Research Priorities

The research needed to provide background and give direction to the National Strategy on Aboriginal AIDS Education and Prevention included both primary and secondary techniques. Facts and knowledgeable opinions were gathered from a variety of primary sources and relevant data and information were uncovered through the literature search and review. This process indicated a lack of information in several areas, which, while not critical to the development of the strategy, impacts the study of AIDS generally in the aboriginal population. In addition, it is important to emphasize that it is not the intention of the Joint National Committee to recommend that this research be carried out as a prerequisite to initiating any aboriginal AIDS education and prevention measure. However, immediate consideration should be given to projects which seek to examine any of the following issues in relation to aboriginal people.

(1) Sexuality and the Sexual Behaviours of Aboriginal People

There are no historical or anthropological accounts of how aboriginal people viewed sexuality and how the arrival of missionaries, tradespeople and others altered these views through the imposition of foreign value systems.

While current statistics are available to indicate the high rates of; STDs (sexually transmitted diseases); sexual abuse and teenage pregnancies among the aboriginal population, no research is available which examines the impact of factors that have resulted in these circumstances.

A thorough analysis of the traditional sexuality of aboriginal people and sexual behaviours today may result in culturally-motivated behaviour change.

In addition, rather than denying the existence of homosexual/bisexual behaviours in aboriginal communities, for example; the leadership and others, will be allowed greater understanding through comprehensive documentation of the facts.

(2) Knowledge, Attitude and Behaviour (KAB) Studies

Studies are needed to measure the level of knowledge aboriginal communities have about AIDS, their attitude towards AIDS and their current behaviours. After education and prevention programs have been implemented, there is a need for additional KAB studies to measure the results of the programs. Has general knowledge increased? Have attitudes changed and have behaviours changed as a result of the prevention message?

These studies are essential in monitoring the effectiveness of education and prevention programs, in understanding certain behaviours, targeting specific messages, and designing effective interventions.

(3) Traditional Medicine and Healing and AIDS

Little is known about the impact of traditional medicine and healing on AIDS but, there is reason to believe that the holistic nature of traditional medicine can be beneficial to the well-being of an aboriginal person who has tested HIV positive. Traditional healers were among one of the first groups to emerge from the aboriginal population as concerned and eager to assist in AIDS intervention. Because there have been claims that traditional medicine has successfully delayed the progress of HIV spectrum diseases and AIDS, there is a need to investigate these claims and document the results.

(4) The Economic Impact of AIDS on the Aboriginal Community

Because AIDS impacts the 25-39 year-old age group, the economic impact of AIDS in a small community could be devastating. In Africa, where 22% of the population have contracted AIDS, the economic impact in an already unstable economy has had disastrous effects. It is essential that this aspect of the disease be examined, so that intervention measures are projected and planned.

The costs of caring for aboriginal people with AIDS in the community should also be examined.

(5) The Implication of AIDS on the Health Transfer Policy - Medical Services from the Federal Government to First Nations

The implications of the policy of the federal government to transfer responsibility from Medical Services to First Nations must be critically examined in terms of future resource needs.

Current transfer funding formulae do not consider the costs associated with health care for people with AIDS and does not cover the costs of mental health care as in AIDS dementia.

Policy and financial issues must be examined in detail to accurately access the transfer implications.

## APPENDICES

References (115)-(121)
Call for Papers and Correspondence (123)-(125)

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CALL FOR PAPERS

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CORRESPONDENCE

## Call for Papers

The following papers were submitted to the Federal Centre for AIDS in response to the "Call for Papers" soliciting ideas and opinions on Aboriginal AIDS Education and Prevention.

Simon Read, A Native Health Organization Perspective on the Prevention of the Spread of AIDS, Nuu-chah-nulth Health Board, Port Alberni, British Columbia; July 1989.

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